

***We don't see ourselves as different:***

**A web of possibilities for disabled women**

**How black disabled women in poor communities equalise  
opportunities for human development and social change**

**Theresa Lorenzo**

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Supervisors: Dr Di Cooper  
A/Prof Harsha Kathard  
Mentors: Dr Hester van der Walt  
Mrs Madie Duncan

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# Declaration

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# Abstract

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This thesis plots a participatory action research (PAR) study that was done in collaboration with disabled women in Khayelitsha and Brown's Farm on the outskirts of Cape Town, South Africa, over a two and a half year period. The aim of the study was to explore how disabled women living in poor communities equalise opportunities for human development and social change. The PAR approach was used to encourage the participation of disabled women to produce new knowledge and consciousness-raising related to the barriers faced and strategies used for their development since acquiring their impairments. The research partners were the SACLA Health Project, the Disabled Women's Development Project of Disabled People South Africa and the Division of Occupational Therapy, University of Cape Town.

The literature review considered the dynamic interchange between poverty, equal opportunities for disabled people, community-based rehabilitation and human development within a human rights approach for disabled women. The review provided the theoretical framework to inform the study design and methodology.

The selection process of the participants used the snowballing technique. Data generation methods included storytelling, narrative action reflection workshops and reflective journalling. Three methods of data analysis were used, namely, six step analysis in the action-learning approach, manual open coding and reflective stance approach.

The first cycle of findings related to the barriers and strategies at three levels of individual, family and community respectively: loss of power, disability as a burden and imposed boundaries; and dispelling myths, disability as gain and extending boundaries. The discussion of the barriers and strategies revealed the complexity of disability and poverty, which created dynamic interchanges between deprivations and potentialities of the women.

Two action stories are presented from the second cycle: firstly, *'Waiting for Transport'* focused on the way the women mobilised for accessible public transport. The second action story described the Arts and Culture cluster in *'Making our voices heard'*. The discussion suggests that disabled women challenged and changed the stereotypes and stigmas of disability when they realised that "our identities are fluid and dynamic". They created a network of action spaces where they gained confidence through collective action, and learnt to listen.

The thesis building is twofold: Firstly, an *Ubuntu* approach to disability is proposed. The approach advocates the interdependency of people, as self and collective identities are formed through human interactions. The recognition of interdependency enables the inclusion of disabled women in human development initiatives. A

spirituality of disability was a source of power in the women, as it enabled the women to see their potential, choices and hopes, as well as nurturing their emotional resourcefulness. These experiences suggest that interdependency and a spirituality of disability need to be seen as driving forces or catalysts to achieve equal opportunities in human development for disabled women.

The pioneering of narrative action reflection workshops, as a new method to generate data of disability experiences collectively rather than on a one-to-one basis, forms the second part of thesis building. The method enables storytelling and action-learning by marginalised groups in impoverished contexts to mobilise collectively for inclusion and equal opportunities in human development.

The study concludes with seven suggestions for further research: redraw the images of disability identity; recreate strong family and community networks for social harmony; retraining stakeholders in understanding disability issues to facilitate equal opportunities; advocate for a public health approach to disability; lobby for accessibility of transport and information as a precondition for equal opportunities, and lastly, to move from provision of food security to sustainable livelihoods and beyond.

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**Keywords:** poverty, disability, women, human development, participation, social change, community-based rehabilitation.

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# Appreciations

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Participatory action research involves collaboration with and support from many people. My sincere gratitude to numerous people and organisations who have contributed to the richness of the research experience and to this thesis. I am immensely indebted.

The disabled women, who participated in the study and, as such, were willing to share their life experiences with others. They continue to inspire and challenge me. Every one of them leads an exemplary life and each one has something to teach others, if we are willing to listen and to learn from them.

The community rehabilitation workers and staff of SACLA Health Project, Marjorie January of DPSA and Peliwe Mdlokolo for your dedication and commitment as participants and co-researchers. Thank you for your patience and endurance with me, and the moments of deep learning.

My supervisors, Dr Di Cooper and Associate Professor Harsha Kathard. Di gave advice, guidance and critical comment on the thesis process. Harsha brought new energy through her conscientiousness and wisdom. Her dedication to dialogue was instrumental in getting the thesis write-up to completion.

My mentors, Dr Hester van der Walt and Madeleine Duncan. Hester's sense of humour and ability to "hold things lightly" unlocked my creativity and potential. Her interest and support accompanied me on this journey from its initial conception to its completion. Thank you for your patience and believing in me. Madie gave invaluable practical help, conceptual clarity and was an excellent sounding board at all times.

Friends and members of DPSA and DiCAG have challenged and nurtured my growth in disability politics. To mention them by name runs the risk of forgetting someone, but I trust that you know who you are. Thank you for teaching me so much. My occupational therapy colleagues in various contexts have stimulated my thoughts in corridor chatter or meetings at UCT, during visits and at conferences. Thank you for entertaining my thoughts and ideas and providing support in different ways. Siphokazi Gcaza, Gubela Mji, Melanie Alperstein and Washeila Sait have engaged in thought-provoking conversations.

Meryl Glaser, Ruth Katzman, Mershen Pillay, Margie Schneider and Nodi Murphy deserve special mention for their helpful comments on the various drafts of this thesis, at different stages of development. Lies Hoogendoorn provided incisive challenges that kept me on my toes. Her brilliance is reflected through comments on the diagrams and in providing the illustrations based on the women's stories. Val Myburgh, Mike and Tarquin Wyeth, of Imago, for enhancing the creativity of posters.

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The Medical Research Council, the National Research Foundation, and the University of Cape Town (through the Merrin Travel Grant and the Emerging Researchers Programme) are acknowledged for different forms of financial assistance that contributed, directly or indirectly, to the completion of this work.

Lorraine Johnstone and Twanette Acker for so willingly opening up your homes to a stranger and sharing your skills in proofreading and layout respectively, so that the write up of the study bears witness to the importance of the message it is attempting to convey. Thank you sincerely for working so professionally in helping me pull this off!

And to Ruth Katzman, for everything! Your support, inquiring mind and attention to detail has made this thesis possible.

## DEDICATION

In closing the appreciations, I would like to dedicate this thesis to Marjorie January, in her roles as a disabled woman, wife, mother, grand mother, as a mentor and disability activist to many people in the field.





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# Definitions of Terms

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## UNDERSTANDING THE NATURE OF REPORTING THIS STUDY: A GUIDE TO TERMS USED

I am aware that the approach to this study with disabled women did not follow the traditional, linear approach to documenting. Participatory action research encompasses an action-learning approach, which is cyclical and iterative in nature. Action, reflection and planning occur simultaneously. Thus in some instances, reporting may seem repetitive as issues are explored in more depth in subsequent cycles. The reader is alerted to the potential confusion around certain terms and time sequencing, which are clarified here.

### **Participatory action research (PAR):**

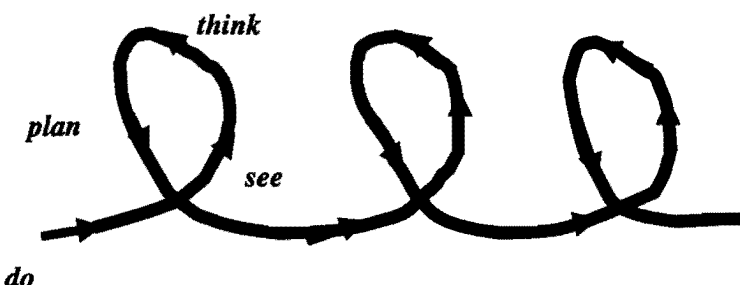
Participatory action research emphasises the emergent processes of collaboration and dialogue that motivate, empower, increase self-esteem and develop community solidarity amongst poor people who have been deprived, oppressed and marginalised (Reason, 1994). Thus PAR provided the framework and approach for the study.

### **Narrative action reflection workshops (NAR):**

Narrative action reflection workshops were conceptualised as a new method that would allow the researchers to generate data on the experiences of disability and development collectively with the women. I define NAR workshops as a combination of action-learning (Hope and Timmel, 1995) and storytelling (Slim and Thompson, 1993) to describe the meaning of human actions linked to larger social concerns (Clandinin and Connelly, 2000).

### **Action learning:**

Different writers have used different terms to refer to the cyclical process of action-learning. I am most comfortable with the four-step process of Hope and Timmel (1995) and Taylor *et al.* (1998), which is repeated: doing, seeing, thinking, planning.



### **Action-reflection:**

Hope and Timmel (1995) identified six principles in Freire's adult education approach. Action-reflection is the fifth principle, following dialogue, where participants reflect on possible actions that they could take towards social change. Thus it is inherent in the action-learning cycle.

### **Reporting different voices:**

The participatory and action oriented nature of this study has created certain tension in honouring the contributions of the research facilitators and the women. I wish to acknowledge this tension upfront, as the process of participation means that it is not possible to distinguish which ideas were mine and which were the facilitators, or the women, as there was so much dialogue and debate. In reporting the process of deciding on methodology and methods for this study (Chapters Three and Four respectively), I have chosen to write as 'we', because the research facilitators discussed and debated different possibilities. In reporting the findings in Chapters Five and Six, there is constant interchange between using the individual voices of the women, where the storytelling or NAR workshops involved individual reporting. Where one woman reported on the discussion from small group activities in the NAR workshops, I report as 'small group'. It was not always possible to indicate exactly how many women were represented as group sizes differ. In these instances, I use 'some' and 'many' to try and give some sense of the level of consensus on an experience. In the discussions and thesis building, there is an interchange between 'we', as the facilitators for ideas and reflections that arose from consultative dialogue groups or planning meetings, and 'I' where I am offering my own position or thought.

### **Human development:**

We used the definition of human development from the UNDP report of 1997 as:

a process of change that enables people to take charge of their own destinies and realise their full potential. It requires building up in the people the confidence, skills, assets and freedoms necessary to achieve this goal. (in Taylor, 2001:49)

### **Disabled people:**

In giving a brief description, I chose to use '*disabled people*' rather than '*people with disability*' thus keeping terminology in line with the social model of disability (Morris, 1998; Priestley, 1999).

### **Disabled women:**

In reporting the findings I chose to use *women* to denote 'disabled women', and *non-disabled* women to denote 'able-bodied women', so as to reverse the norm which usually defines a 'disabled woman' as different.

**People with impairment:**

I may use this term occasionally to differentiate disability as a social construct from reference to a disabled person.

**Public health practitioners:**

I decided to use the term public health practitioners to refer to any worker who is involved in some way or another with the women at a community level. This includes professionals such as doctors, occupational therapists, physiotherapists, social workers and nurses as well as community health workers and community rehabilitation workers.

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# List of Abbreviations

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ANC	African National Congress
AU	African Union
CBR	Community-based rehabilitation
CoDEP	Community Disability Entrepreneurship Project
CRW	Community rehabilitation worker
DICAG	Disabled Children's Action Group
DFID	Department for International Development
DG	Disability grant
DPO	Disabled People's Organisation
DPSA	Disabled People South Africa
ILO	International Labour Organisation
INDS	Integrated National disability Strategy
MDF	Masiphatisane Disability Forum
NEPAD	New Economic Programme for African Development
NGO	Non governmental organisation
ODP	Office of the Deputy President
RDP	Reconstruction and Development Programme
RURACT	Rural Action Group on Disability
SACLA	South African Christian Leadership Assembly
SALTI	St Luke's Leadership Training Institute
SCAMP	Student Christian Association Mission Programme
TRC	Truth Reconciliation Commission
UCT	University of Cape Town
UNESCO	United Nations Education, Scientific and Cultural Organisation
WHO	World Health Organisation

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# Prologue

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## TRANSITIONS IN THE MAKING OF A DISABILITY RESEARCHER: MY STORY

### Who am I?

I grew up in Benoni, a town on the East Rand outside Johannesburg. I come from an average middle class family of seven children. I have a twin sister who trained as a nurse, at the same time as I trained as an occupational therapist. I love the outdoors, especially cycling and hiking, which is probably why I was drawn to community work – the opportunity to be outdoors to interact with people, and overcome obstacles and challenges together, while getting to know each other and different aspects of life simultaneously.

### Why am I telling my story?

Before I share the story of this thesis, let me tell the story of how I developed competence to research disability. I have discovered that my competencies include having a sense of humour and the ability to ‘hold things lightly’ (most of the time)! I have been told that I am an eternal optimist – maybe it is something I have learnt from the disabled women with whom I work! I present my story with an awareness of the vulnerable position in which I place myself. I wrote my story prior to the start of the study, so that I could become more aware of my assumptions and motivations for doing disability research. It was a meaningful journey of self-reflection. I analysed the personal journals that I kept for seven years while working in a rural community-based rehabilitation (CBR) programme. I used the reflective stance approach (Meulenberg-Buskens, 1999) to identify the patterns, trends and shifts in my experiences of disability and development. The questions I posed for the analysis were:

- What did I learn about disability and development?
- How did my experiences shape my ideas about disability research?

I hope that in reading, you are stimulated to reflect on your own story of work and involvement in the challenges of poverty, disability and human development.

### Becoming an occupational therapist

I studied for a BSc in Occupational Therapy at a South African university in the early 1980s. The medical model of disability formed the framework for the curriculum, which was divided into physical rehabilitation and psychological rehabilitation. Psychological rehabilitation focused on psychiatry, mental illness and intellectual disabilities. There was very little reference to the socio-political context within which we would practise. Reflecting on my professional socialisation now, I am struck by the marked absence in the curriculum to



conscientise occupational therapy students towards social, economic and political development. Ironically experiencing failure in my final year of undergraduate studies introduced me to the political struggle in our country and the opportunities and challenges of development work, especially in rural areas. It was during a practical placement at a psychiatric hospital, while repeating six months, that a psychologist raised my awareness of the political struggle and the inequities in health and social service for the majority of South Africa's population. This experience highlights how opportunities often arise out of perceived and real adversity, as it opened a new perspective on my practice as a health professional.

I qualified in the mid-eighties, at the height of the political struggle in South Africa, uncertain about where my future career as an occupational therapist would take me. I was aware that I had been largely 'protected' from the harsh extent of discrimination and oppression of black people, by race as a white South African and by the reductionistic approach in training. My initial job was in a general hospital in one of the urban townships of Johannesburg for nearly two years. I found the job stimulating. It planted the seeds of interest in honing my research skills. One critical incident in this regard was the opportunity to treat many young black youths who sustained upper limb amputations from throwing hand grenades during political protests in the townships. They were further disabled, since we were not allowed to issue upper limb prosthesis to them as these were considered 'dangerous items' in prison. No one in the team, including myself, thought to advocate for the prisoner's rights to optimal rehabilitation.

### **Integrating my spirituality and politics**

My spiritual practice has been enriched by my Christian upbringing, initially shaped by the Catholic faith, and later by Anglicanism, as I searched for integration of my spirituality and emerging political conscientisation. My political journey was closely woven with my spiritual journey. Different mission programmes exposed me to the social and political injustices of apartheid. They provided the early opportunities to grapple with the social, economic and political realities of poverty and the social injustices of South Africa. I seemed to experience my spirituality as a source of strength, hope and inspiration.

Eighteen months after qualifying, I spent three months in Hong Kong working in a home for disabled children as part of the Student Christian Association Mission Programme (SCAMP). I was the minder of Cindy, a five year old girl with Down's Syndrome in a home for children and adults with physical and intellectual impairments. I had to drive her across Hong Kong mainland to Hong Kong Island. I discovered new abilities in myself: squeezing from six lanes of traffic into two, in order to go through the tunnel that went under the sea. All the time Cindy would be chattering away to me in Mandarin, not at all concerned that I didn't understand or barely responded. We had many laughs together. Interactions with the team members of a playschool challenged my professional development and insights regarding rehabilitation and development. I came to appreciate the possibilities and opportunities for the inclusion of disabled children and adults into mainstream society.

## Growing in my understanding human development

My growth in understanding the relevance of human development for occupational therapists was closely linked to a decision to move towards working in community-based rehabilitation (CBR). New opportunities and challenges of development work in rural areas opened up for me in 1987. My attitude and approach to disability was reshaped in the next seven years when I took a research post at a rural hospital in Limpopo Province in the northern part of the country. The health district was a five hour drive north of Johannesburg (450 kms). It was the period when I cut my teeth in human development, disability politics and the disability rights movement. I was a research fieldworker for a study on the prevalence of disability under the auspices of the university where I had studied. Once the research was completed, I decided to stay on so as to initiate community outreach services. I worked together with a team of occupational therapists, physiotherapists, speech and hearing therapists, and specialised auxiliary support staff.

Our work involved the development of CBR services, culminating in the training of community rehabilitation workers (CRWs). These were formative years in shifting my practice from an individual rehabilitative approach to a human rights approach, as I struggled to discern my role as an occupational therapist. I was trained to treat impairments and had not yet developed skills in promoting the rights of disabled people. I also had little understanding of sociology and the politics of poverty and development. Yet, the rural areas provided an abundance of opportunities for development projects. They were overwhelming for a young practitioner like myself:

*It has been difficult at times because I feel that it's been a testing ground ...I feel I have failed – I haven't made any significant progress in language study, although there have been plenty of ideas for service e.g. refugee work with the Catholic Mission, sewing classes in the villages, integrated bible study groups, prayer groups, involvement in a church Sunday School maybe. (11 January 1988)*

I experienced inner conflict between the understanding of my professional role and the needs of the disabled people. I struggled to make sense of my spiritual journey and my professional work. I wrote further:

*If I stay in occupational therapy and work among the people up here, can I consider this to be [God's] work that I am involved with the oppressed and the poor for social justice? (1 February 1988)*

The growth of deep, meaningful cross-cultural friendships with a diverse range of people whose beliefs were different to my own, gently challenged me to reflect on my beliefs and values. There were three women, in particular, who as mentors had an impact on my transformation in conscientisation. They each brought a different perspective to life and enriched my appreciation of the diversity of faiths and cultures of community living and working. My spiritual journey also involved diverse reading, and Henri Nouwen's work was particularly influential, as I was able to relate to his concept of the wounded healer (Nouwen, 1976). Self-development through individual and group therapy processes and courses provided further enrichment.

I grappled most of all with the social and economic hardships of apartheid for black people, let alone disabled people and their families, in the communities around the hospital. The harshness of the impact of poverty on the lives of disabled children, their mothers and disabled adults and other family members was almost soul destroying. I began to see that the components of equal opportunities and social integration of community-based rehabilitation (CBR), identified by the International Labour Organisation, United Nations Educational, Scientific and Cultural Organisation and World Health Organisation, (ILO/UNESCO/WHO, 1994), could make a direct contribution to the human development of disabled people, if practitioners moved beyond medical rehabilitation on a one-to-one level aimed only at fixing the impairment. I learnt to think laterally and to persevere in problem solving:

*I'm not sure what my reaction is supposed to be to today's problem of transport for the Rivoni visit [A centre for blind entrepreneurship training]. That all the [hospital] kombis were either in the garage or being used, and that [HSDU] wouldn't let us use any of their kombis, made me frustrated and despondent, because there's no ways I could go to the group and tell them we couldn't go, when they were really looking forward to it. So I acted on a comment from Junior [a disabled person in the group] about asking the Chief and, voila, a kombi was organised through the Chief with the taxi drivers. And the comments here: 'now that's really community development – getting the people to organise themselves.' (8 November 1988)*

My approach to human development was deeply influenced by the work of Hope and Timmel (1995), which incorporated Freire's approach of conscientisation and radical transformation. Their approach of action-reflection cycles began to shape my thinking and practice. The destruction of family and economic systems caused by the migrant labour system was seen all around the rural villages. It was hard not to feel guilty about the opportunities I had had as a white South African. I struggled to know how to respond to poverty and to be involved with people in addressing their needs in a relevant and meaningful way. I recorded:

*So many times now I have felt washed out and totally ineffective ... I don't seem to be touching sides anywhere! I have never felt so pressurized in work ... I have struggled to understand the poverty and suffering and resignation of the people...*

*I think that ... time spent up here has given me insight into the destructiveness of apartheid – the breakdown of family life and morality because of the migrant labour system and also the difficulties Esther<sup>1</sup> has had to cope with because of the full responsibility of the family being on her shoulders. (April 1998)*

Such experiences were in contrast to my own. I found that my family was one of my strongest support systems, as they were a source of strength, love and encouragement:

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<sup>1</sup> Esther, a nursing assistant who worked as a translator with me, was the sole breadwinner in the family as her husband had been a migrant labourer. He was unemployed at the time of working with her.

*I thank [God] for the support of my family and the effort they make in encouraging me. They have helped me see how negative we [the therapists] can be and how this can bog us down. Often we need to change our mindset to be more positive and have a positive attitude rather than changing my place of work or taking a holiday because that doesn't resolve the root of the problem. (1 February 1988)*

My emerging political conscientisation was fuelled by my interactions with Disabled People South Africa (DPSA), which led to me to understand disability as a form of social oppression. The Rural Action Group on Disability (RURACT) provided regional and national forums for discussion, debate and social engagement between disabled people who were members of DPSA and service providers from the health, education and welfare sectors primarily. I was initiated into disability politics 'on the ground', as the seminars facilitated the link between apartheid, poverty and disability. I was simultaneously encouraged and challenged by the late Maria Rantho, the first co-ordinator of the Disabled Women's Development Programme of DPSA, who went on to become the first disabled female member of parliament for the African National Congress (ANC) after the first democratic elections in 1994. My continued involvement with the disability rights movement has meant that I continued to grapple with the 'health and disability' debate (Lorenzo 1991; Lorenzo, 2001), as well as the power dynamics in service delivery and partnership development (Lorenzo and Cloete, 2004). I began to realise that change was a complex, intricate process that occurred on multiple levels:

*I'm disappointed that the people didn't go on the co-op workshop because of a misunderstanding about money and registration. The lack of trust and good communication and not really working together co-operatively is killing me. At times I despair and wonder if we're being foolish about what we are trying to do. Can we break the system/network of perceived corruption, dishonesty and mistrust? All of this has been detrimental to sound, healthy relationships. (18 April 1989)*

My time in the rural areas also involved the training of undergraduate health science students from one of the universities in rural health and human development. Final year medical, occupational therapy and physiotherapy students did three and four week rural blocks at the hospital respectively. Training students was an opportunity to hone my skills in interdisciplinary teaching and intersectoral practice, as well as in managing conflicts and tensions between academia and disability activism. My experience as a facilitator in CRW training programmes, as well as capacity building workshops for the Disabled Children's Action Group and lecturing in CBR and disability studies, provided opportunities for me to reflect on how the occupational therapy profession needs to change.

### **Grounding my experience as a disability researcher**

The seven years of working in a rural area was a life-changing experience for me. While still working there, I registered for the Higher Diploma for Educators of Adults at a South African University's Faculty of Education. Subsequent to this, I was fortunate to be awarded a Helen Suzman Cheyenne Leadership Scholarship Award from the British Council to study for a Masters in Disability Studies at the Centre for International Child Health, University of London. This was fortuitous as I was feeling burnt out from piloting

different aspects of a rural CBR programmes in South Africa. I had questioned whether I wanted to continue practising as an occupational therapist in CBR. Doing postgraduate studies in London provided the distance and space for self-reflection. The time was rejuvenating as I integrated a range of emotions of humiliation, guilt, shame, pain, anger, despair about South Africa and being a white, able-bodied South African woman. In the run-up to the first democratic elections and the subsequent celebrations in April 1994, there was a hope against all hope that things could be different and that we were able to heal each other through connecting as human beings, irrespective of differences.

In reflecting on the diversity and oppression of disabled women in South Africa, especially those in rural areas, I became increasingly convinced that these women have much to contribute to our understanding of disability in the context of poverty, human development and the role of practitioners in health and CBR. The challenge from the Disability Rights Movement to build capacity of disabled people has been a constant challenge and motivation to me. I took a job at South African Christian Leadership Assembly (SACLA) Health Project when I returned from London and later joined University of Cape Town (UCT) while maintaining a training position with SACLA. Straddling the two worlds of academia and an non-government organisation (NGO) practice provided the opportunity for me to meet and work with the Disabled Women's Development Programme of DPSA in Cape Town. A growing interest in initiating a Disability Studies programme in partnership with DPSA in South Africa started to emerge.

### **Why have I told this story?**

For me, CBR has been about demystifying practice, professionalism and research as vestiges of power and privileges that serve only to alienate and exclude certain people. If we are not conscious of the different forms of power, we may further oppress disabled people through our practice and research. The writings of many disability activists and academics has conscientised me to how disabled people have been alienated and excluded from research, when researchers and practitioners remain unaware of the power of language and education. It is not an unknown struggle amongst those researchers who have tried to hold the tensions of academic rigour and participation (Stone, 1997; Stone and Priestley, 1996; Priestley 1997). I would hope that anyone in civil society would be able to pick up this thesis and feel that they could benefit from reading it. They should not feel intimidated by academic research. I would also hope that practitioners and researchers would be encouraged to work in authentic partnerships with disabled people at grassroots and nationally, and in so doing, embrace the transitions and differences that have potential to enrich our lives. As Hartley (2002) comments while knowledge is power, sharing knowledge is progress. Thus, I have attempted to write this thesis in a way that honours the various interactions and opportunities I have had to engage with disabled people. The critical turning points and lessons that I share here have shaped the values and beliefs that informed the approach to this study.

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# Chapter Outline

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The thesis comprises eight chapters, which are outlined below.

## **Chapter 1      Background to the study**

The chapter provides the contextual background to the study. It describes the evolution of the study and introduces the partners in the research process. The chapter concludes with framing the purpose, aim and boundaries of the research.

## **Chapter 2      Theoretical considerations and critical issues: reviewing the literature**

This chapter presents a review of the literature around the four issues of critical significance to this thesis, namely, poverty in the context of disability in South Africa, human development, equalising opportunities in human development and implementing rehabilitation within a social model of disability framework. The Human Scale Development Approach is introduced as a conceptual framework, as it provides an appreciation of the complexity of human development and poverty. The UN Standard Rules On The Equalisation of Opportunities For Disabled People are briefly described.

## **Chapter 3      Exploring Participatory Action Research as a suitable research methodology**

The process of developing a suitable methodology for the study is described. It uses the theory of co-operative inquiry and liberation education to justify Participatory Action Research as the methodology of choice. The influences of critical theorists in emancipatory disability research are discussed. The chapter ends with the potential pitfalls in PAR.

## **Chapter 4      Methods to generate data: research design**

The chapter provides a detailed description of the research design. The research facilitators and participants are introduced. The four phases of the PAR study are outlined. The methods used to generate data are described, followed by an explanation of the data analysis and interpretation process. The different theoretical frameworks that were used for analysis are indicated. The process of verifying authenticity and the ethical considerations are given.

## **Chapter 5     Discovering the barriers to and strategies for equalising opportunities: findings and discussion**

There are two parts to this chapter, which presents the findings and discussion. The first part of the chapter consists of three iterative cycles that describe the personal experiences of the women in equalising opportunities at an individual, family and community level respectively. The second part of the chapter presents a discussion to explore the complexity of disability, as seen in the different dimensions of deprivations (barriers) and potentialities (strategies) that the women experienced.

## **Chapter 6     *This project is very busy*: findings and discussion**

The chapter describes the actions taken by the women in response to the participatory nature of the research. The first part presents two action stories: firstly, '*Waiting for transport*' focuses on the way the women mobilised for accessible public transport. The second action story describes the Arts and Culture cluster in '*Making our voices heard*'. The action stories illustrate the changes that occurred in the lives of the women and research facilitators. The second part of the chapter discusses two key areas of interpretation that contribute to building the thesis of this study, namely, the foundation for presenting a new approach to exploring how women equalise opportunities for human development.

## **Chapter 7     A web of possibilities for disabled women: thesis building**

The penultimate chapter comprises the two parts of thesis building by integrating the complexity of disability and poverty and the significance of the actions that the women engaged in as a web of possibilities. Part One explores how the interdependence of *Ubuntu* and a spirituality of disability, hopefully, deepens our understanding of how the women are able to equalise opportunities for their development.

Part Two of the thesis building positions narrative action-reflection workshops as a potential new method that is relevant as a data generation method for disability research, as well as a strategy to equalise opportunities for disabled women in development.

## **Chapter 8     On the Road of Hope: suggestions for further action**

This chapter proposes seven signposts as suggestions for further research to sustain the momentum of action-learning amongst disabled women and other stakeholders that have been ignited through this study, so as to contribute to the theory and practice of human development.



*I made a pot with three legs... it is a CRW, disabled women and [the facilitators], so it is for us to cook with this pot... if one leg is broken, it can't stand on it's own (CRW).*

*Doing is first thinking and then planning and then afterwards you develop so that the end product can be a success. But it can also be possible that the end product is unsuccessful (Small group).*

*And the other thing is that things said here are developing and building us inside...the other thing is that these things are relevant to us exactly deep down in our hearts. They are encouraging us (Bongiwe).*

*We were encouraged as disabled women to share ideas and that is when that candlelight came up and we were then able to see (Small group).*



University of Cape Town

# Chapter 1

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## Background to the study

### Introduction

#### The study partners

Disabled People South Africa

SACLA Health Project

Division of Occupational Therapy, University of Cape Town

#### The evolution of the Participatory Action Research study

#### Context for the study

The African Renaissance

The Africa Decade on Disability (1999-2009)

#### Policy Context

### Problem statement

#### Why the study is important

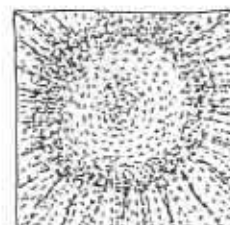
#### Purpose of the study

#### Formulating the research question

### Aims and Objectives

### Boundaries of the study

### Reflective summary





## Chapter 1

# Background to the study

### INTRODUCTION

This chapter describes the evolution of the study and the different contextual factors that pointed to the need for the research. The study took place at a time when the country was in transition while the first five-year period of a democratic government was celebrated. The hopes and expectations that things would be better were encapsulated in the slogan of the African National Congress: *"A better life for all"*. This slogan needs to be seen alongside the challenge of Disabled People South Africa (DPSA) with their slogan *"Nothing about us without us"*. The growing strength of the Disability Rights Movement nationally and internationally has been successful in portraying disability as a political, human rights issue, and not only as a welfare and medical concern. The influence of the Disability Rights Movement on the development of new policies in South Africa in the years after the first democratic elections in 1994 is described. The three partner organisations are introduced, leading to the purpose and aim of the study. In the same way that the Movement has lobbied for inclusive education, there is a need to lobby policymakers and higher education institutions for inclusion of disabled people in mainstream development initiatives. The boundaries of the study are given. In this thesis, I present the stories of the disabled women who experience barriers and strategies to their development, and the changes that occurred as a result of the Participatory Action Research (PAR) study.

### The Study Partners

The three partners that participated in the study are briefly introduced here: The community rehabilitation workers (CRWs) of the South African Christian Leadership Assembly (SACLA) Health Project, the Disabled Women's Development Programme of DPSA and two staff members of the Division of Occupational Therapy at the University of Cape Town. See Figure 1. The research facilitators and disabled women are more extensively described in Chapter Four.

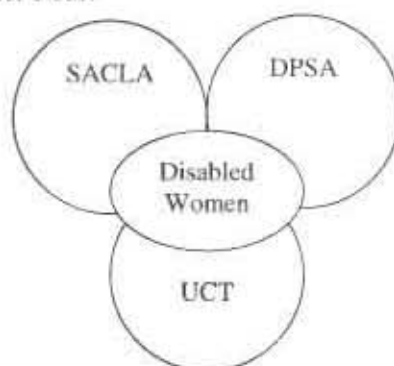


Figure 1: Research partners

### ***Disabled People South Africa (DPSA)***

DPSA was formed in 1984 in response to the discrimination that disabled people experienced, especially black disabled people. They mobilised and organised as a 'resistance group' against oppression on the basis of race and disability. Their main focus of activity was on political education, particularly in the deep rural areas and townships of the country. There are currently more than 250 community-based self-help initiatives of disabled people across the country registered as members of DPSA (Cockburn, 2003). As the leading national cross-disability political organisation in South Africa, DPSA has become a powerful mechanism for ensuring the achievement of human rights and development of disabled people. There are nine provincial structures, with the Disabled Children's Action Group (DiCAG) recognised as a sister organisation that lobbies for the rights of disabled children through their parents. DPSA was a strategic partner in the research, firstly, because the question was raised by Marjorie, and secondly, because many of their programmes seek to address poverty alleviation and economic empowerment of its members. The organisation plays a critical role in advocating for the integration of disability issues in the policy development process.

### ***South African Christian Leadership Assembly (SACLA) Health Project***

SACLA is a grassroots, primary health care, non-government organisation (NGO) operating in various informal settlements in the Khayelitsha and Nyanga districts. It was established in the 1980s to provide accessible primary health care services to the poor. The name was adopted from the conference of SACLA in 1979. Dr Ivan Toms was the founder and director. The project trained local community members as community health workers. In 1987, Marion Loveday, a physiotherapist, initiated the training of community rehabilitation workers (CRWs) in response to needs identified by the community. The community of mothers of disabled children and disabled people elected a mother to be trained to work in the area where she lived.



**Community Rehabilitation Workers from SACLA doing home visits**



The minimum level of education required was Grade 4 to ensure functional literacy. The team grew to include occupational therapists and social workers. The focus of activities shifted from home visits and referrals to include daycare centres for the children, income generation groups for disabled adults, and disability advocacy and awareness campaigns. Thus there was growing acknowledgement of equal opportunities and social integration, as essential components of community-based disability support programmes (Hermanus, 2000; Lorenzo and Saunders, 1999; Loveday, 1991; Loveday, 1993). SACLA has worked mainly with children and adults who have physical and intellectual impairments. The reason for this focus may be attributed to the fact that a physiotherapist was responsible for the initial training. But, beyond this, the Khayelitsha and Nyanga districts are serviced by different non-government organisations, such as the League of the Friends of the Blind and Cape Mental Health. There is also a School for Deaf children and DEAFSA responds to deaf adults.

The Community Disability Entrepreneurship programme had humble beginnings. The first steps towards facilitating income generation for disabled adults known to SACLA were taken in 1992 with support from a small group of CRWs and an occupational therapist at the time. Two groups of disabled people in Site B and Site C in Khayelitsha received training and seed money to start a leatherwork project and a sewing project. Developments were hampered by political violence in the run up to the first democratic elections of 1994. Community development training in 1995 helped to identify the number of skills for income generation that the CRWs had amongst themselves. Some of the CRWs had worked in small business projects before joining SACLA. Therefore, they were willing and enthusiastic to help facilitate the development of small business development groups, a new role for them. Over a period of eighteen months, three groups were formed in collaboration with the Occupational Therapy Division at the University of Cape Town (Van Niekerk *et al.*, in press; Lorenzo *et al.*, in press), as another research and development initiative. SACLA provided a home base for the study, and played an important role in service delivery. As such, their experience provided fertile ground for understanding the factors that influenced opportunities for human development and policy implementation.

#### ***The Division of Occupational Therapy, University of Cape Town***

In 1995, the SACLA Health Project initiated a partnership with the Division of Occupational Therapy of the University of Cape Town as a training and research affiliate. With the political changes in the country, higher education institutions were faced with the need to change their curricula to ensure relevance in the training of future practitioners and policymakers. The Division of Occupational Therapy was no exception. A change management consultant facilitated an exploratory weeklong workshop in April 1996, involving UCT, DPSA, service providers in the disability field and disabled people living in Khayelitsha, Nyanga and Gugulethu (three of the peri-urban areas of Cape Town in the Province of the Western Cape). Participants looked at addressing disability issues in public health services and poverty initiatives at a community level. NGOs such as Cape Mental Health and DiCAG were involved. In October 1996, the Masiphatisane<sup>2</sup> Disability Forum was

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<sup>2</sup> Xhosa meaning 'holding together', which reveals the spirit of co-operation in a group. The initial workshops were co-ordinated by the SACLA Health Project to facilitate NGOs working in disability to begin working collaboratively with



constituted to address the need for better co-ordination of services and strengthen support systems through the participation and self-representation of disabled people in decision-making processes. The Forum meets every second month to look at issues of disability related to service delivery, public awareness and advocacy, skills development and accessing resources (Saunders, 1998). Through a prolonged process of engagement, the three partners decided to initiate a collaborative study to explore the experiences of disabled women in poverty and development initiatives.

### **The evolution of the Participatory Action Research study**

The evolution of the study needs to be seen within the context of the African continent internationally, and the new policies that were created with the birth of democracy in South Africa, which had ramifications for the human development of disabled women. Marjorie (MJ), the provincial chairperson of the Disabled Women's Development Programme of DPSA (Western Cape), and I were concerned about the experience of disabled women in leadership and development opportunities. The study involved an organic process based on a question raised by Marjorie on the participation of disabled women in leadership and development opportunities offered by DPSA and other NGOs. There was also a newly established district health system and a growing awareness of disability as a human rights issue rather than a welfare and charity issue (Office of the Deputy President, 1997). The SACLA Health Project was one of the primary health care NGOs providing services in the new health districts.

We were also curious about the level of participation of disabled women in the Masiphatisane Disability Forum. It was recognised that the women were not fully integrated into the structures of formal society, e.g. development initiatives, business development, women's wellness groups and church groups, which support and provide for women's needs. From our observations of the participation of the women in the Forum, we agreed that we would explore how the women were maximising the opportunities for human development.

### **Context of the study**

Disabled women who share their stories of human development in this study live in wooden shacks in the peri-urban areas of Khayelitsha and Brown's Farm in Nyanga, Cape Town in the Province of the Western Cape (See Figure 1a). Many of these women are single mothers who look after more than just their own children. They are also responsible for members of their extended family. Many disabled women living in these informal settlements have migrated from the rural areas of the Eastern Cape in the hope of finding better medical care and economic opportunities to alleviate their poverty. The UNDP report of 1997 (in Taylor, 2000:49) defines human development as:

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disabled peoples organisations. After the first year, the chair for each workshop was rotated to build the capacity of disabled people in leadership and development.

a process of change that enables people to take charge of their own destinies and realise their full potential. It requires building up in the people the confidence, skills, assets and freedoms necessary to achieve this goal.

The report implies an ability on the part of a country to provide an environment in which its citizens are able to access opportunities and resources and make choices to live decent lives. Taylor (2000) adds that human development recognises that people need economic, social, cultural, political and human rights in order to develop to their fullest potential, and to live meaningful lives. She identified access to water, knowledge, health care, employment and other productive resources as basic ingredients for human development. In South Africa, these rights were denied to the majority of the people.

South Africa's rate of poverty is 45%, which means that more than 18 million citizens (or 3 126 000 households) live below the poverty line pegged at an income of R353 per adult per month (Taylor, 2000). In rural areas the figure rises above 50%. Black disabled women are often thought to be triply oppressed on the basis of race, gender and disability. Poverty would be a fourth form of oppression. Cape Town has been described as a very divided city, with extreme multi-dimensional poverty experienced in Khayelitsha and Nyanga, with a population of approximately 711 244 people (De Swardt, 2002). The average number of people per household was found to be 4.62. General housing conditions are poor. The majority of households use paraffin for heating (80%) and cooking (65%), as it is cheaper than electricity. But there is greater risk of accidents and fires as a consequence. In total, 60% of households have access to toilets, but for 19% access to a communal toilet is difficult and for 11% there is no access at all. 35% obtain water from communal taps. More than 76.4% of households fall below the official poverty line. Most households experience outright poverty or vulnerability to poverty, as income stability is volatile and precarious. In 32% of households the main breadwinner had lost his/her job at some point during 2002. Only 19% of adults have had four years or less of formal education (De Swardt in Haricharan and Rendall-Mkosi, 2002). The research found that the low level of education impacted minimally on the ability to find paid work. The highest rate of vulnerability was related to food security: A total of 70% of households went without sufficient food during a year; 43% of households have a food shortage. Lifestyle problems, high levels of communicable diseases (HIV, TB and TB/HIV combined: 39% in Khayelitsha and 40% in Nyanga) and trauma (assaults were estimated at 29% in Khayelitsha and 26% in Nyanga) are the main causes of death and place a triple burden of disease on poor communities. Social grants provide some alleviation. Violence in the community and household is common and often goes unchallenged (Abrahams *et al.*, 1999; Lorenzo and Saunders, 1999; De Swardt in Haricharan and Rendall-Mkosi, 2002).

In response to poverty, many women work informally in activities such as spaza<sup>3</sup> shops, hawking and handcrafts. The struggle for economic independence seems to be that much harder for disabled women, who have a right to equal opportunities for development (Cockburn, 2003). There are many households who use the income of one

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<sup>3</sup> Spaza shops are small retail shops selling basic foodstuffs and household needs, usually from a front room or garage of a house.

individual, such as disability grants and old age pensions, to survive and send children to school (Loveday, 1993; Lorenzo and Saunders, 1999; Lorenzo, 2004). Many different NGOs operate in Khayelitsha and Brown's Farm, but their services are unco-ordinated.

### ***The African Renaissance***

The African Renaissance has been seen as a call to the people of Africa to work towards the reawakening of Africa, economically, socially, politically and spiritually (Mbeki, 1999). Such revitalisation through African-linked socio-economic development by exploiting our resources and harnessing the productive capacities of the people is essential (Makgoba, 1999). The core of the African Renaissance is the focus on people-centred development, which is also one of the driving principles in the White Paper On An Integrated National Disability Strategy (ODP, 1997). It is in this context that we need to consider the position and potential contribution of disabled women in the African Renaissance. Mazwai (1999:417) comments "it is the work on the ground in which ordinary people participate that will herald [the reawakening of Africa and its people]".

The promotion of human development involves various sectors such as education, health, social development, labour, public works, transport and housing. Netshitenzhe, (1999) calls for mobilising communities in the development processes, facilitating internal and external trade and promoting self-determination and human rights. The challenges of economic transformation are massive poverty, high unemployment, large-scale illiteracy, unskilled people, huge debt and poor infrastructure (Gueye, 1999). Strategies and questions that have been raised relate to the need to minimise the extent of human suffering, focus on the psychological development of people, as well as producing competent individuals involved in the overall development in their community. Gueye (1999) claims that the State should provide energy, transport and communication to stimulate economic activity. How this reality is experienced in the lives of disabled women is what the research set out to explore. An abundance of literature supports the claim that impairment and disability may create and exacerbate poverty as it increases isolation and economic strain. Conversely, poverty may lead to impairment and disability (Coleridge 1993; ODP, 1997; Stone, 2001; Tiroler, 1995; Werner, 1992, Wilson and Ramphela, 1989). At the time of writing up this research the **New Economic Programme for Africa's Development (NEPAD)** is being discussed globally. Thus we will argue that there will be no African Renaissance if disabled women continue to be marginalised and excluded from mainstream human development. Gender and disability need to be included as part of all sectors of society, since disability impacts on families and societies, not only individuals.

### ***Africa Decade on Disability (1999-2009)***

Internationally, the Disabled People's International (DPI), consisting of the national Disability Rights Movements from different countries had been successful in placing disability on the agenda of the United Nations. A UN Decade of Disabled Persons occurred in 1982. The Disability Rights Movements in Britain and America were influential in integrating disability into social policy. These movements were led by middle class, white males (Oliver, 1999; Morris, 1998). In contrast, DPSA aligned themselves with the liberation struggle, and as such, were challenged to influence policy development and implementation in the

context of extreme poverty and social oppression. DPSA developed strong links with the African National Congress (ANC) prior to the 1994 elections. There was a strategic focus on integrating disability issues into the Reconstruction and Development Programme (RDP) following the first democratic elections. DPSA has been instrumental in setting up an Office on the Status of Disabled People (OSDP) in the President's Office, as well as in each of the Premiers' Offices in the nine provinces. Disabled people have also been elected as members of parliament. Both mechanisms have provided a framework for the inclusion of disability issues into policy development and research, as described above (Cilliers, 2004).

The UN decade on disability (1983–1992) seemed to have little impact on the quality of life for disabled people in Africa. DPSA, together with disability organisations in South Africa and in partnership with other Disability Movements from the African continent, were instrumental players in initiating the Africa Decade on Disability (2000–2009) declared by the African Union (AU). The decade presents an opportunity for disabled people in Africa to develop an African approach to disability issues and create greater access to opportunities for disabled people. It has the support of the United Nations. DPOs will be one of the main actors in implementation of the Decade, together with African governments and the African Rehabilitation Institute - the technical arm of the African Union.

The Africa Decade aims to focus on education, skills development, employment and access to rehabilitation, which includes access to assistive devices and equipment. The development and institutional capacity building of DPOs has been identified as one of the activities. This capacity building would have a specific focus on the emancipation and empowerment programmes for disabled women and youth. Poverty alleviation and economic empowerment have been recognised as critical activities of the Decade, which should include putting disability on the political, social, economic and cultural agenda of countries. The Decade hopes to contribute to implementation of participatory research programmes to generate meaningful social change for disabled people and their families. The Decade recognises the promotion of CBR as an important activity. Thus this study has potential to make a meaningful contribution to building research capacity of DPOs in the delivery of CBR.

## **Policy Context**

Disabled people generally, face a situation characterised by extreme levels of inequality and discrimination. We considered some specific international and national policies that seemed to bear some relevance on the scope of this study. These policies were selected in line with DPSA's advocacy campaigns to prioritise disability awareness, economic empowerment, education, transport and sign language. While the policies inform the intentions of different ministries of government, there is an absence of meaningful strategic guidelines and resources dedicated to implementation for addressing the needs of disabled people generally.

The **United Nations Standard Rules on Equalisation of Opportunities for Persons with Disabilities** (UN, 1994) imply a strong moral and political commitment on behalf of member states to take action to equalise

opportunities for disabled people. The policy informed the theoretical framework for the study and is discussed further in Chapter Two. The Rules define the “equalisation of opportunities” as:

the process through which the various systems of society and the environment, such as services, activities, information and documentation, are made available to all, particularly to persons with disability. (UN, 1994:21)

The policy provides a holistic approach to integration of disability issues. The shortcomings of this policy are that implementation is dependent on the goodwill of governments, and there is no systematic capacity building of service providers and DPOs to use the framework as a guide for programme development in public and community service organisations.

The situation is clearly illustrated by the implementation of **community-based rehabilitation (CBR)** programmes in many developing countries, which has been strongly influenced by the ILO/UNESCO/WHO (1994) policy on CBR. Even though the policy recognises CBR as a strategy within community development, programme implementers have focused selectively on rehabilitation, without recognising that it is only one of the preconditions for the equalisation of opportunities and social integration of disabled people (Hartley *et al.*, 2002; Ndaziboneye, 2002; Lorenzo, 2004). The definition goes on to state that CBR involves the combined efforts of disabled people themselves, their families and their communities, and the appropriate health, education, vocational and social services. Yet DPOs have levelled criticism at professionals who have implemented CBR without consultation and ownership by disabled people and their families (Hartley, 2002; Thomas and Thomas, 2000). With few exceptions, CBR has been implemented in South Africa mainly through the efforts of NGOs and DPOs, with little involvement and commitment from government or universities. There is little doubt that CBR is a relevant strategy for Africa in facing the challenges of poverty alleviation and the development of disabled people, if implemented by all critical stakeholders (Finkelflugel, 2004). WHO (2003) revised the approach to CBR to focus primarily on equal opportunities and poverty alleviation.

The **Bill of Rights** in the South African constitution identified socio-economic rights, which incorporate the right to housing, health care, education, social security and employment, as basic human rights (Cilliers, 2004). The Standard Rules provided the framework for disability policy development in post-apartheid South Africa. Since 1997 the **White Paper on an Integrated National Disability Strategy (INDS)** (ODP, 1997) states that the situation faced by disabled people in South Africa is one characterised by extreme levels of inequality and discrimination. Disabled women, especially black women and those staying in rural areas, have experienced higher rates of exclusion. The INDS provides a guide to the different ministries to ensure that the rights of disabled people are protected and promoted by recognising their contribution to development of the country. The White Paper makes recommendations for the integration of disability issues in the development of specific policies and legislation. There are specific guidelines for the implementation of CBR as an approach to address inequities in service delivery. Despite this, CBR and disability programmes experience severe funding cuts and lack of government support, as there is minimal allocation of resources, professional

squabbling and no recognition of CBR workers (Rule, Lorenzo and Wolmarans, forthcoming 2005). The approach of DPOs has been stronger on advocacy and human rights through self-representation and economic empowerment and leadership development. (Cornelje, 1993; Miles, 1996; Philpott, 1992; Rule, Lorenzo and Wolmarans, forthcoming, 2005). Chapter Two critiques these matters in greater depth.

Historically, health and social services were inequitable, under funded and insensitive in their response to the majority of the population in South Africa. There has been discrimination in the provision of services to different racial groups, which impacted most severely on black disabled women and children (ODP, 1997). Segregation and marginalisation of the majority of the population resulted in less than adequate services. The situation is not dissimilar to so-called developed countries in the North, where young black disabled people experience inadequate dissemination of information as a major barrier (Vernon and Swain, 2002). South Africa's **National Health Plan** (Department of Health, 1997) has proposed constructive changes: the development of district health services provides an opportunity to correct the inequities experienced by disabled people and their families in relation to access to health and rehabilitation services. The plan recognises rehabilitation as a priority programme, as one of the four components of primary health care (PHC) that has received inadequate resources in the past. The Mental Health Care Act protects the rights of people with intellectual and psychiatric impairments. The **National Rehabilitation Policy** (Department of Health, 2000) has recognised CBR as a strategy for service delivery, although the focus is still on rehabilitation, rather than equal opportunities. However, there has not been a reallocation of resources nationally to ensure implementation of the different policies. Instead it is left to each of the nine provincial governments to commit the necessary resources.

Other government departments have also needed to formulate policies to ensure disability equity. The **Employment Equity Act** (Department of Labour, 1998) has begun to address the discrimination faced by disabled people when applying for a job or in the workplace. The Department of Labour has formulated the **Skills Development Act** (Department of Labour, 2000) that earmarks learnerships for people from historically disadvantaged groups, including disabled people. The National Council on Higher Education needs to implement recommendations in the White Paper on Inclusive Education (Department of Education, 2002). The criticism leveled at many of these initiatives is that the implementation is slow because of poor resource allocation, capacity building of public service staff on issues related to disability equity and little commitment to change this aspect of diversity. The overarching policy framework for **Transport** provision in South Africa is based on the premise that transport is a means to an end, not an end in itself. It envisages a smooth and efficient interaction between the various components making up the transport systems and people's needs. However, there are no clear imperatives concerning accessibility needs of disabled people.

## **PROBLEM STATEMENT**

### **Why this study is important?**

Poverty as a major barrier to the human development for black, disabled women in poor communities has been recognised in international research (see Chapter Two for review of these issues). But little significant work has been focused on South Africa specifically. Research on CBR in South Africa has alluded to the interconnections of poverty, development and disability generally, but the experiences of disabled women have not been studied in significant depth. Speaking about poverty and human development in South Africa, Taylor (2000) stated that it is important that poor people report for themselves whether there has been any change for them.

In the call for equal opportunities of disabled people into poverty alleviation and development programmes, it is important to determine the nature of the barriers and strategies of disabled women, as a group that experiences higher rates of exclusion (ODP, 1997). In fact, there is little evidence that the concept of integration into mainstream development initiatives has benefited disabled women. In the very least, the feasibility of mainstreaming, as outlined in recent new policies described earlier, needs to be researched in contexts of scarce resources and deep levels of deprivation. Much has been written about community participation as an essential ingredient for sustainability of development programmes and increased productivity in development programmes globally. Participatory processes in development and research in partnerships between DPOs and professionals have been dogged by the fears and concerns of professionals that there will be a drop in standards with the sharing of skills and that their jobs, positions and status would be jeopardised (Hartley *et al.*, 2002; Ndaziboneye, 2002; O'Toole and McConkey, 1995; Wirz, 2000). In contrast, service delivery in large areas of the country remains minimal, especially in rural areas (Lorenzo and Cloete, 2004; Rule, Lorenzo and Wolmarans, forthcoming 2005). Price and Kuipers (2000) indicate that if CBR is to gain meaningful recognition by policymakers and other relevant decision-makers, then theories have to be developed in CBR, which take a very practical approach to implementation of service delivery to date. In addition, there is an absence of meaningful measures of social change for disabled women and their families.

### **Purpose of the study**

The purpose of this study was twofold in relation to the concern about the participation of disabled women in poverty alleviation and development opportunities. The first aspect focused on the local context to describe the lived experiences of poverty and disability of disabled women who live in informal settlements on the outskirts of the City of Cape Town. Very little is known about the experiential dimensions of human development for disabled people generally. The study sought to identify the barriers that the women faced and the strategies that they utilised for poverty alleviation and human development at a local level. Simultaneously, the influence of critical stakeholders of CBR programmes in human development was explored, since SACLA (NGO), DPSA (DPO) and UCT (a higher education institution) were collaborative

partners in the research. We reflected on the nature of capacity building strategies to ensure meaningful transfer and implementation of skills by the women. The study sought to generate an understanding of factors that contribute to sustained social change by disabled women themselves. A second aspect of the study addressed Oliver's (1997; 1999) criticism of research on disability that has used data generating methods involving one-on-one interactions between the researcher and the researched, yet generalizing the findings to speak for the collective experiences. Our study has contributed to the development of a research methodology that was able to generate data collectively from the lived experience of women, while simultaneously benefiting them. A method was created to be compatible with fostering their participation in action for change. Thus this study hopes to contribute to an understanding of how collective experiences are able to support policy implementation, so as to maximise resources and the inclusion of disabled women in opportunities for development.

**Implications of the study are multi-dimensional.** The study has potential to be expanded in meaningful ways to promote the inclusion of disabled women in poverty alleviation and human development initiatives. It hopes to provide suggestions relevant for non-governmental organisations (NGOs) and disabled people's organisations (DPOs), as important organs of civil society. The findings should contribute to increasing the understanding and awareness of disability issues for people involved in policy development and implementation across the various sectors of government. Those involved with academic studies in disability, diversity, gender and social development may also benefit. The study could be an asset in training all professionals and practitioners, so that more equitable partnerships with disabled people, generally, are developed.

### **Formulating the research question**

The identification of research questions was organic in the sense that the design allowed for flexibility and iterative evolution of the research questions throughout the PAR process. New questions emerged as the process of data collection, analysis and interpretation unfolded (Polit and Hungler, 1997). The research process started with a broad question raised by the DPSA provincial chairperson of the Disabled Women's Development Programme. The overarching question that formed the focus of the thesis became:

*How do disabled women equalise opportunities for human development?*

### **AIM AND OBJECTIVES**

The study sought to determine how women who were living in impoverished communities equalised opportunities for human development since their impairment (see Table 1). The partners hoped to record the actions and changes that occurred as the women engaged in an ongoing action-reflection process, so as to explore a data generation method that promoted participation and change simultaneously.



**Table 1: Aims and objectives**

<b>AIM: To determine how disabled women in poor communities equalize opportunities for human development.</b>	
<b>Phase</b>	<b>Objectives</b>
Phase One	Discover how the women perceived the factors that hindered their development (barriers). Discover how the women perceived the factors that fostered their development (strategies).
Phases Two and Three	Describe the actions taken to remove the barriers and to strengthen the strategies for the women's development. Describe the changes that occurred for the women.
Phase Four	Make recommendations related to advocacy, policy development, service delivery and training. Disseminate findings to relevant stakeholders.

## **BOUNDARIES OF THE STUDY**

The study originated out of an expressed need from the chairperson of the Western Cape Provincial Disabled Women's Development Programme of DPSA. The focus is justified in the light of the current deliberation on equity for disabled people in the country, specifically children, youth and women. While race and gender have been debated vigorously, disability still needs to be accepted as an issue of diversity and equity.

We are aware that the study has focused on one province in South Africa, while providing some indication of relevance for South Africa and Africa more broadly. We hope that others will be encouraged by these stories and stimulated to do similar studies in other areas. We are cautious to look at the implications globally, as issues of disability, poverty and human development are so context specific (Hartley, 2002; Price and Kuipers, 2000). In the same vein, we are conscious that while disability cuts across many sectors, we have focused more specifically on CBR, as this was the initial field of practice of the three research facilitators. While the influences of the disciplines of sociology, psychology, feminism and anthropology are relevant, as the primary researcher, I was aware of my limitations in drawing on these different perspectives in depth, as it reached beyond the scope of my competence. Rather, the study has sought to focus on theoretical and practical contributions drawn from the experienced needs of disabled women that have local relevance, directly, and national relevance, indirectly.

## REFLECTIVE SUMMARY

This chapter presented the evolution and context of the study. It described the political considerations that influenced the focus of the study, together with a brief description of the partner organisations. The relevance and purpose of the study were identified in formulating the research aim. Lastly, the boundaries of the study were defined.

Chapter Two will expand on some of the critical theories, issues and concerns raised here.

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Figure 1a: Map of study area

## Chapter 2

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# Theoretical Considerations and Critical Issues: Reviewing the Literature

### Introduction

#### A human rights approach for disabled women

Poverty in the context of disability in South Africa

Human development

Implementing community based rehabilitation

Considering equal opportunities for disabled women

### Reflective summary



University of Cape Town

# Theoretical Considerations and Critical Issues: Reviewing the Literature

## INTRODUCTION

The objectives of the Reconstruction and Development Programme will not have been realized unless we see in practical terms the condition of women in South Africa changing for the better, and that they have the power to intervene in all aspects of life as equals.

(President Nelson Mandela, 1994).

This chapter provides a review of the literature focusing on four aspects of the study, within a human rights approach: firstly, poverty and disability, human development, community-based rehabilitation and equalising opportunities. These strategic and key issues related to the dynamics of inclusion/exclusion, which bear relevance to the focus of this study on disabled women and their well-being. They are represented here diagrammatically as a diamond in Figure 2. The diamond symbolises how knowledge and experience is multi-dimensional and can refract light on the nature of this study. A human rights approach is relevant within the South African context due to the focus on the Bill of Rights in the new constitution.

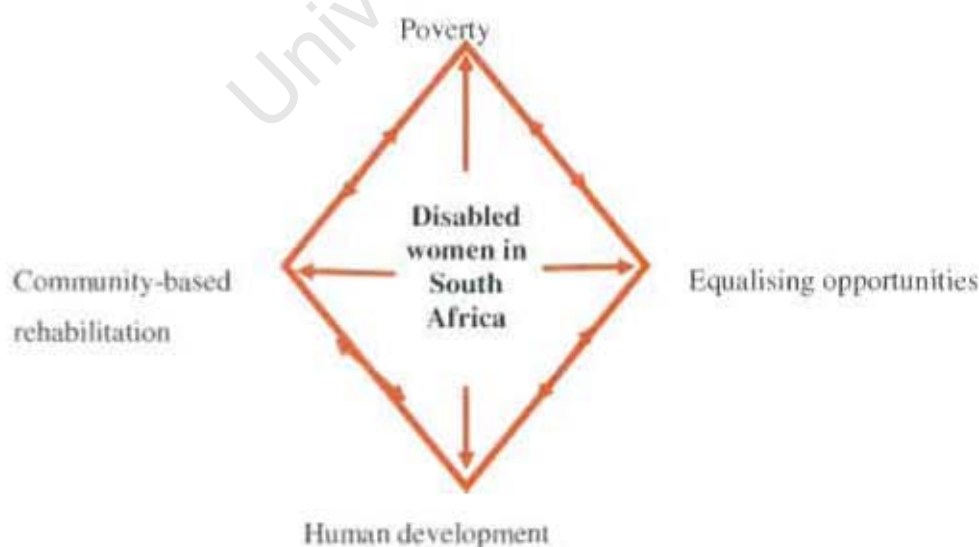


Figure 2: A human rights approach to disability

In considering the literature, together with the theoretical and policy frameworks that would inform the study, two questions proposed provided a useful guide regarding, firstly, what would the study contribute to our knowledge about the human development of disabled women in South Africa and Africa broadly? Secondly, in what ways does it present information or insights that will contribute towards the implementation of policy to ensure equitable service delivery and sustainable practice?

There has been little written about the social divisions and experiences of discrimination related to disability as a form of 'other', particularly in southern hemisphere countries. The focus has been largely on race, gender, sexuality and class. While there was acknowledgement in the 1990s of the need to listen to women from more diverse backgrounds, disability still seems to be marginalised and underreported globally (Abu-Habib, 1997; Asindua, 2002; Morris, 1998; Mpagi, 2002; Read, 2000). Many writers mention that women, including mothers of disabled children, are considerably creative in employing active strategies and a range of tactics to manage difficulties related to their well-being and development (Beresford, 1994 in Read, 2000; Priestley, 1999; Thomas, 2002). Beresford (in Read, 2000) suggests that services that enhance and strengthen the preferred and characteristic coping mechanisms of families were more likely to be sustainable. However, few elaborate on the nature of these strategies, as this study will set out to try and achieve, by tackling the fact that disabled women living in poverty have been underrepresented in many studies on poverty and development (Goosen and Klugman, 1996; Nosek, 2003; Read, 2000; Thomas, 1998).

Stone (1999) raised the importance of contextualising the stories of disabled people and their families in which disability is seen as a social, cultural and development issue. She suggested that such accounts would consider the socio-economic changes and impact on a household; family perceptions of impairment and their responses to it; available support systems; policies and family demands. She found that there was a need to:

make connections between individual stories and the wider contexts in which these stories are situated, produced and find meaning...[as well as] recognise the complexity, changes and contradictions that characterise reporting world realities (Stone, 1999:190).

These key issues are discussed within the context of the African Renaissance and recent policy development processes, as described in Chapter One. The review draws on literature describing experiences in Britain, the Middle East, Asia and Africa. Only English-language literature was critiqued in terms of its relevance to the South African context. Searches were done through PubMed and Google.

## **A HUMAN RIGHTS APPROACH FOR DISABLED WOMEN**

### **Poverty in the context of disability in South Africa**

Development co-operation between NGOs and governments locally, nationally and internationally has been driven by the agreed purpose to combat poverty. In a review of CBR programmes, Stienstra *et al.*, (2002)



boldly claimed poverty alleviation cannot be achieved if disabled people are excluded. It is estimated that 70% of disabled people and 87% of disabled children live in poorer countries of the 'south'. Disabled people constitute 16% of the population in extremely poor countries and are seen as an economic burden to their families (Stienstra *et al.*, 2002). The cycles of exclusion and poverty are exacerbated, as the family's ability to participate in education and employment is also impacted on negatively. Unfortunately, not much has changed since Nkosasana Dlamini-Zuma (in Meer, 1998:10), as Minister of Health South Africa in 1995, in preparation prior to the Beijing Conference, stated:

Women in South Africa are definitely not free. The majority lives in poverty and cannot read or write. Millions do not have proper housing or access to water, sanitation, education, or health services. They are marginalized with no right to own their land under customary law, subject to the authority of male relatives.

Transforming the process of development to a human scale (local level), therefore, needs to ensure that deprivation and oppression of women, particularly disabled women are tackled. In looking at human development in South Africa, Taylor (2000) proposed that people's perceptions of change and transformation should be examined to determine how they have engaged in the process of change. Lack of educational and employment opportunities restrict poor women's chances of creating an independent life. Access to resources differs from individual to individual, so it would be important to try to establish the grounds of claims of multiple oppressions, if they do exist. Abu Habib (1997), writing on Palestine, found that a sound development programme is one that identifies and addresses the vulnerabilities of disabled women. This insight indicates that the intangible aspects of poverty and human development must be considered in this study.

**Emotional vulnerability due to poverty** is often not voiced or given the serious attention that it deserves. The consequences of poverty go beyond mere material deprivation. They reach to the core of a person's being, affecting their human need for identity, affection, creativity and understanding of themselves and others (Max-Neef, 1991). It leaves people feeling vulnerable and dependent, as their sense of security and means of survival remain tenuous. The expenditure of effort and personal resources within the domestic sphere is often seen as unpaid emotional labour that involves hard work, restrictions and a hidden labour of love, but not real work (Doyal, 1995; Read 2000). Women who have engaged in informal care work have been a particularly powerless and hidden group, whose rights and aspirations have only been recognised in the recent past (Read, 2000). The role of the carer is seen to involve a multiplicity of skills, including handling the emotions of others, smoothing tension between family members and providing refuge from and counterbalance to the strains of the public sphere. Morgan (1996 in Read, 2000) extends the concept of emotional labour to disabled people who are cared for as well, as they have to cope with as much as the carers, but in different ways. However, Morris (1993 in Read, 2000) feels that the concept of "care" should not be used when it means assistance or control of the disabled person. Begum (1990 in Read 2000:88) coined the term "burden of gratitude" that a disabled person may experience when not in control of choices



related to personal assistance and care needed. Ideally, disabled people need the opportunity for reciprocal relationships with those close to them, without being distorted by the demands and emotional labour intrinsic to informal care. This aspect is explored further in looking at interconnections to women's health here and later in the chapter.

The 1995 South African Participatory Poverty Assessment (Taylor, 2000) reported that millions of citizens are plagued by continuous ill health, experience extraordinary levels of anxiety and stress, accompanied by the realities of violence and abuse mainly on women and children, and work for low incomes. There is a pervasive sense of hopelessness because of an inability to sustain living conditions. Furthermore, Taylor (2000) found that there was a deep sense of despondency, alienation and disenchantment linked to a sense of the slow pace of change. Bundy (in Taylor, 2000:56) gave a vivid picture of the realities of intense poverty and inequality:

Its texture: the dull ache of deprivation, the acute tensions generated by violence and insecurity, the intricacies of survival and all its emotions – despair, hope, resentment, apathy, futility and fury.

In a study on the wellness activities of disabled women in Canada, Odetta *et al.*, (2003) found that research in the health and well-being of disabled women has not increased, despite a growing interest in women's health. In exploring the meaning of health for disabled women in the United States of America, Nosek *et al.*, (2004) identified the importance of social support and societal attitudes were essential for a positive mental state. Read (2000) found that mothers of disabled children in Britain often experience social isolation, as the informal support network activities available to non-disabled mothers were not necessarily readily available to them. She recognised that mothers from minority ethnic groups and low-income families are least likely to be members of self-help and support groups as they live on limited budgets and, therefore, are not able to buy into practical sources of help and diversion for themselves and their children. Chang *et al.*, (2003) explored community-based approaches to helping women who experienced domestic violence in the United States of America. The barriers experienced by disabled women in these studies related to health practitioner's lack of knowledge about disability issues as well as access to services, inadequate information and insufficient resources exacerbated the situation for disabled women. Policymakers and practitioners need to understand the extent of alienation or lack of social capacity that exists in deprived communities, particularly for families where there is someone living with an impairment.

Another aspect of well-being of disabled women that is often overlooked in human development is the role of **spirituality**. One of the reasons given is it is too intimate an area in a person's life. Yet, Max-Neef (1991; 1995) recognises it as a central dimension of being human and thus integral to satisfying human needs. There has been a reluctance on the part of researchers to focus attention on such subjective phenomena as beliefs, values, fantasies and spirituality, as there is an element of embarrassment that keeps them from probing the complexity of the problem itself (Selway and Ashman, 1998; Ver Beek, 2000). An exception was a study done by McColl *et al.*, (2000) on the experiences of people with traumatic-onset disability from spinal cord

injuries and head injuries. They developed a matrix to reflect the five themes from their findings: awareness, closeness, trust, purpose and vulnerability. These themes were related to three relationships found in literature on spirituality, namely, the intrapersonal, interpersonal and transpersonal. In a study on how disabled individuals and those with chronic illness survived and coped successfully with their lives in Australia, do Rozario (1997) identified the combined elements of spiritual transformation, hope, personal control, positive social supports and meaningful engagement in life that made the difference. Another reason may be that the concepts of spirituality and religion are often used synonymously, leading to some confusion. Spirituality is an area that will be explored in this study, as African spirituality forms an integral part of many people's lives.

Despite the hardships, the poor have shown resilience, courage and perseverance in their struggle to survive. However, little is known about the specific experiences of poor disabled women, as they have largely been excluded from research and development opportunities (Thomas, 2004). There are also reduced opportunities for getting income from paid employment outside the home (Lorenzo and Cloete, 2004; Read, 2000). It would be important to determine whether the women in this study shared similar experiences, so as to facilitate inclusion in poverty alleviation and development initiatives. Thus an essential aspect of this study is to understand how disabled women approach poverty and disability as part of human development.

## Human development

In considering participation of individuals and communities in human development in South Africa, Taylor (2000) recognises that the poor may not have the same capacity as active and informed citizens or organised formations, in decision-making at every level of society. It is in this context, that the challenge for social action to change the attitudes and approaches to disability seems more daunting. **Human scale development** (HSD) offers a refined understanding of a people-centred development practice. An interdisciplinary team of Latin American researchers formulated the approach led by Chilean economist Manfred Max-Neef (Van Zyl, 1994). Their approach to development is about people and not about objects, with a concern for improved quality of life, especially for poor people. Quality of life is determined by the opportunities people have to satisfy their fundamental human needs, which involves complex and interwoven processes of development. Much emphasis is placed on development processes on a human scale or local community level, rather than large national or international developments (Van Zyl, 1994). HSD theory considers the fact that we live in a period of transition when paradigm shifts are necessary and indispensable to avoid a disintegration of society (Max-Neef, 1991).

The theory of HSD identifies nine fundamental human needs, namely, subsistence, identity, protection, affection, freedom, leisure, creation, idleness and understanding. Definitions of these needs are given in Table 2. According to Max-Neef (1991), these fundamental human needs are universal, the same in all cultures and historical periods. Each need has a twofold character that is held in constant tension, enabling the elimination of the vicious cycle of poverty. Max-Neef (1991:24) defines the twofold character firstly as

deprivation. *Deprivation* is a physiological response to an unmet need that is usually experienced as a sensation, something that appears to be missing. Secondly, a *potentiality* indicates the degree to which these human needs engage, motivate and mobilise people, and eventually become a resource.

**Table 2: Definitions of fundamental human needs (TCOE, 2001)**

Identity:	The need to feel that you yourself are important, that you are worth something, that you have something to offer.
Affection:	The sense that you are appreciated, accepted, loved; the need to have close friends or people that you love and who love you.
Protection:	The need to feel safe, secure; not scared that you are in danger.
Subsistence:	The need for food, shelter, water – the things commonly referred to as “basic needs”, without which a person can die.
Understanding:	The need to understand what is going on around you as well as the need to be understood by others.
Creation:	The need to be creative, to make things, invent things, use your own ideas and imagination.
Participation:	The need to be part of what’s happening, to belong to something, to take part in decisions that affect you; the need not to be isolated or ignored.
Idleness:	The need to rest, reflect, relax, take time out, play, do nothing.
Freedom:	The need to be free and not restricted; free to make your own choices and not have everything said and decided for you.

Satisfiers refer to a diverse range of means used to meet these fundamental human needs, which are culturally determined and vary according to time, place and circumstances. They can be seen in societal processes or practical ways or means that people adopt or choose to structure their lives (Van Zyl, 1994). Singular satisfiers meet one need while synergistic satisfiers meet more than one need at a time. Satisfiers are seen as negative in nature, if the outcome is unhelpful or causes pathology, e.g., violence. Societal and individual pathologies occur when needs are not met or when they are met in a negative way for a long period of time (Max-Neef, 1991). Satisfiers are positive, if the satisfier leads to beneficial and constructive outcomes. The existential dimensions by which needs may be met include:

1. *Having*: what we have – indicates institutions, customs, norms, mechanisms, non-material tools and laws (not physical facilities or goods and services).
2. *Being*: through the way we feel or regard ourselves and the attributes and attitudes that are used to define one, whether individual or collective.
3. *Doing*: through what we do – defines actions, whether individual or collective.
4. *Interacting*: where and with whom we interact – indicates collective locations or environments as settings in time and space.

Max-Neef (1991) and Hope and Timmel (1995) contend that real development will only happen if all nine fundamental human needs are met. Beside subsistence, the fundamental human needs are not seen as hierarchical, but rather each need is regarded as equally important (Max-Neef, 1991). The theory looks at addressing poverty by meeting deeper human needs rather than just material aspects, economic goods or services. The approach seeks to develop self-reliance by overcoming human poverty in all its forms. HSD theory talks about *poverties* in relation to any fundamental human need not being adequately met, not just subsistence needs (Max-Neef, 1991). HSD addresses the scarcity of resources, as human needs are seen as life forces that become resources to mobilise people to act to meet their needs. HSD adds the dimension of *synergy*, where the creative and synergic social potential that exists, but lies dormant in people, is stimulated so that limited resources are stretched further. In this way, the human capacity of people to solve their own problems is mobilised (Van Zyl, 1994).

At a global level (Chambers, 1995; Giacaman, 2001; Kabeer, 2000) and local level (Barberton *et al.*, 1998; Meer, 1998; Lorenzo, 2003, 2004; Rule, *et al.*, in press; Taylor and Conradie, 1997), the experience of oppression leaves poor people with little choice and few opportunities for participation in empowerment and development programmes. Recently, the experiences of poverty and development of disabled people has been placed on the political agenda, globally (Coleridge, 2004; DFID, 2000; WHO, 2003) and locally (ODP, 1997). Coleridge (1993) and Hope and Timmel (1995) have claimed that for development to occur in developing contexts such as Africa, it is crucial that people need to understand the causes of their underdevelopment, and with that understanding, work to change their situation by having control over their own lives. Coleridge (1993) draws on experiences from different countries in the Middle East, Southern Africa and Asia. He believes that action on disability needs to bring hope to the community about its capacity to solve immediate problems. He has witnessed the struggle of disabled people in impoverished communities for personal dignity, in a context of disempowerment from social inequality, injustice, violence, and the "wearing down that comes from a life lived on the edge of survival" (Coleridge, 1993:113.) Various studies have shown that patriarchal and cultural rituals are significant barriers to women's development generally (Abrahams, 1999; Chang *et al.*, 2003; DFID, 2000; Ramphele, 2002). In proposing a theoretical agenda for Disability Studies, Thomas (2004) and others (Doyal, 1983; Ingstad, 1999; O'Toole and McConkey, 1995; Stone, 2001, Werner 1995) note that there has been little written on the vicious cycle of poverty and disability, although the majority of disabled people live in impoverished conditions in 'developing' countries.

Literature reveals an appreciation of the complexity of women's lives, where there may be huge differences in circumstances and practices. Speaking about the South African situation, Meer (1998) and Mda *et al.*, (1996) comment that these systems serve to entrench inequalities, which keep women in inferior positions and may be exaggerated in the case of disabled women. In the political context, from the 1950s, women in South Africa struggled against injustice and resisted apartheid, which led to banning, imprisonment and exile for many women (Meer, 1998; Taylor and Conradie, 1997). They made their voices heard within the liberation movement in exile as well as the trade unions and community based resistance in the country



during the 1980s. Women inspired each other to work to create a new South Africa. Amidst the violence and personal struggles there have been victories such as the increased number of women in government at local, provincial and national level since 1994. Even before the democratic election, recognition of the role of women as mothers and wives has been high on the agenda of disability activists. An Office on the Status of Women and the Commission on Gender Equality were set up within the Presidency (Meer, 1998). Disabled women have gained self-representation in these structures through the advocacy and lobbying of DPSA (Cilliers, 2004; Cockburn, 2003).

Drawing from the struggle against the oppression of apartheid that many black women experienced in South Africa, there is a need to create a critical mass of disabled women who would understand disability as another source of oppression and cause of their underdevelopment (Lorenzo, 2003; ODP, 1997). The vicious cycles of dependency, isolation and poverty are very hard to overcome with few resources. It is imperative that ways are found to correct such inequity. It is the hopeful intention of this study to make a significant contribution in this regard. To date, no study on poverty and disability has used HSD as a framework for analysis, neither have studies on poverty and development included disability issues in their application of HSD. Thus this study hopes to determine the relevance of Max-Neef's approach in the analysis of the experiences of disabled women, as it has potential to make a significant contribution to CBR developments as a strategy for poverty alleviation for this marginalised group.

### **Implementing community-based rehabilitation**

The different experiences in the past two decades have seen considerable changes in approaches to disability and services to disabled people. These shifts have created enabling environments and community action for development that have acknowledged the rights of disabled people. Approaches to CBR have been diverse within community development, as it is more than a service – it is about 'how' the needs of disabled people are met, more than 'what' is done (Hartley 2002; Price and Kuiper, 2000; Thomas and Thomas, 2000).

Many of the changes in understanding disability can be attributed to the growth of the Disability Rights Movement internationally (Charlton, 1998; Finkelstein, 1993), as well as the development of Disability Studies programmes internationally (Barnes and Mercer, 2004; Lorenzo *et al.*, in press). Oliver, (1990) was instrumental in developing the social model of disability, which called for a shift in paradigms from seeing disability as a tragedy and individual issue, to seeing it as a social and political issue. Subsequently, a number of disabled academics and others have contributed to alternative theoretical frameworks in order to challenge existing approaches to disability and service delivery (Barnes and Mercer, 2002; Barnes and Mercer, 2004; Barton and Oliver, 1996; Lang 2000; Oliver, 1996). The social model of disability proposed by the Disability Rights Movement does not place the onus for inclusion on the disabled person as an individual, but rather on changes at a societal level.

One of the common weaknesses of CBR programmes in Africa is that they have been initiated and supported by NGOs and DPOs on a small scale with limited involvement from government (Finkelflugel, 2004; Hartley, 2002; Haricharan and Rendal-Mkosi, 2004). Since its inception, CBR has been an approach that has focused on delivery of rehabilitation services in poor countries. It has been implemented in contexts which are diverse, complex, dynamic and uncontrollable, with professionals who are generalists, and more likely to be women (Thomas and Thomas, 2002; Wirz, 2000). Ironically, while rehabilitation was identified as the fourth component of primary health care, it has not been given the same attention or resources as a strategy for health equity for disabled people (Werner and Saunders, 1995; Hartley, 2002). Some stakeholders, especially the Disability Movement, perceived such a narrow focus on medical rehabilitation as the major weakness of CBR, especially in poor urban communities (Evans, *et al.*, 2001; Rule, *et al.*, in press). The Movement maintains that equalising opportunities would result in substantial changes in the social, economic, cultural and political spheres of life, than the present focus on medical rehabilitation in CBR programmes (Cilliers, 2004; Cockburn, 2003). A focus on equal opportunities in CBR would reinforce disability as a political crosscutting issue that becomes the responsibility of civil society, public and private sectors and all ministries of government (ODP, 1997; WHO, 2003). Such an approach would promote the full social inclusion of many other marginalised and oppressed groups, and contribute to poverty alleviation strategies.

The literature calls for clarification on the roles of stakeholders in CBR and the relationships between these roles. Common stakeholders who have been recognised include the disabled person, their family and community, as well as community rehabilitation workers, volunteers, and professionals who work for NGOs or different government services (Asindua, 2002; Coleridge, 1993; Finkelflugel, 2004; Hartley *et al.*, 2002). DPOs feel strongly that disabled people are not merely recipients of CBR, but contribute to its sustainability, as the skills, philosophy and attitude remain behind when external facilitators leave (Ndaziboneye, 2002). If the different stakeholders were taken seriously, there is real potential to foster the development of disabled women to overcome the vicious cycles of the poverty and disability issues (Stone, 2001). With the growth of the Disability Movement, there has been a call for partnerships with professionals whose role would be as a resource person, to share their knowledge and skills as determined by DPOs and families of disabled people. Already, Swain (1993) has warned that this would not be easy for professionals. Such partnerships need to be extended to other policymakers, researchers and practitioners in health and development. This study could make a further contribution in this regard to ensure that disabled women gain access to opportunities and resources.

The involvement of institutions of higher education in contributing to equal opportunities for disabled people is conspicuous by their absence. Yet, these institutions carry the responsibility of training the future generations of professionals and service providers (Chang *et al.*, 2003; Nosek, *et al.*, 2004; Odetta *et al.*, 2003). Only recently have some training institutions in South Africa included CBR and the social model of disability in their curricula, together with exposure to practical opportunities with NGOs and community

projects (Duncan *et al.*, 2005; Lorenzo and Cloete, 2004). Cornielje (1999) has been one of the lone voices calling for CBR to be seen as an effective strategy for public health in developed countries as well. A study by Smith *et al.*, (2004) on safe motherhood and reproductive services for disabled women in Zambia found that while the barriers were social, attitudinal and physical in nature, their vulnerability to sexual exploitation was compounded by their desire for children and affection. The need to include these issues in curricula for health professionals was identified. Nolan and Nolan (1999) found that disability in nursing curriculum in the United Kingdom is associated with chronic illness in meeting the rehabilitative needs of disabled people. In looking at medical student education on disability in Australia, Crotty *et al.*, (2000) identified that assessment and management of disability focused on disability as a chronic disease that required multidisciplinary team care. Peterson and Quarstein (2001) found that professionals tend to be inured to the difficulties and experiences by disabled people in business and government, and need to learn to show both verbal and non-verbal sensitivity in the workplace. It is hoped that this study will contribute to the identification of meaningful and realistic strategies to foster partnerships between stakeholders to maximise mutual gains for human development of disabled women. Disability research focused on the aspect of partnerships could be expanded further in order to contribute significantly to poverty alleviation.

The challenge for CBR and disability programmes in tackling human development is to identify relevant indicators of empowerment and social change (related to *Rule 20* below). The root of the challenge lies in needing to define what would be seen or meant by 'success'. In the Middle East, Abu Habib (1997) claimed that success could be measured by the fact that women went to school, found jobs, developed and maintained friendships and had intimate relationships with a partner at some stage during their life. She found that women who succeeded said that it was their disability and not gender that was their major barrier. Success was also determined by the financial independence and status of women. In contrast, Ingstad (1997) found that disabled people in Botswana considered life free from struggles and problems as an indicator of success. The differences in these perspectives could be attributed to the fact that much of the literature and training materials that have been developed and disseminated have been based on Western models of practice and belief systems (Leavitt, 1999). This focus has undervalued what poor disabled women in Africa have to offer. Hopefully, this study will be a step in affirming Africa's knowledge and experience to the global community.

It bears repeating that Taylor (2000) identified access to education, health care, work opportunities, housing, basic necessities such as food and water, as human development indicators of the needs reflected by poor people themselves. Giacaman (2001) describes the potentially serious problems that emerged in the implementation of CBR in Palestine. The expectation of voluntary care places a burden on women who are already in a vulnerable position further excludes women from economic and social life. The second problem was the absence of state structures in providing for the basic needs of disabled people. The situation raises the issues of charity versus social rights of citizens that disabled people should be granted. He states that such a social rights approach would strengthen social movements such as the Disability Rights Movement. Evans *et al.*, (2001) express McConkey's drawback of involving actors in CBR evaluations as people may

imagine change when no real empowerment has improved. They advocated looking at three dimensions in the evaluation of CBR programmes in poor urban communities in India, namely, technical quality, interpersonal quality and management quality. McColl and Boyce (2003) identified five dimensions of disability advocacy in organisations representing disabled people. Three dimensions were related to ideological positions, while two practical dimensions were membership and resources.

### Considering equal opportunities for disabled women

The UN 22 Standard Rules On The Equalisation Of Opportunities For Persons With Disabilities, (UN, 1994) was promulgated in 1993. The Rules are divided into three sections (See Table 3): The first four rules focus on the preconditions for participation; the next eight rules look at the target areas for participation and the last ten rules describe implementation measures. (Appendix 1 presents a brief description of each rule).

**Table 3: The three categories of the UN 22 Standard Rules (UN, 1994)**

Preconditions	Target areas	Implementation measures
<p>Rule 1: Awareness raising</p> <p>Rule 2: Medical care</p> <p>Rule 3: Rehabilitation</p> <p>Rule 4: Support services</p>	<p>Rule 5: Accessibility</p> <p>Rule 6: Education</p> <p>Rule 7: Employment</p> <p>Rule 8: Income maintenance and social security</p> <p>Rule 9: Family life and personal integrity</p> <p>Rule 10: Culture</p> <p>Rule 11: Recreation and sport</p> <p>Rule 12: Religion</p>	<p>Rule 13: Information and research</p> <p>Rule 14: Policymaking and planning</p> <p>Rule 15: Legislation</p> <p>Rule 16: Economic policies</p> <p>Rule 17: Co-ordination of work</p> <p>Rule 18: Organisations of persons with disabilities</p> <p>Rule 19: Personnel training</p> <p>Rule 20: National monitoring and evaluation<sup>4</sup></p> <p>Rule 21: Technical and economic co-operation</p> <p>Rule 22: International co-operation</p>

The Rules acknowledge that disabled people live in different contexts in different countries, and that the disparities between rich and poor countries impact on the quality of life and equal opportunities for disabled people. The Rules are not law, but rather provide a moral obligation for the government and civil society to ensure that people get access to the same service, help and information to facilitate their participation in society. Thus, disabled people should be expected to meet the same obligations and responsibilities as other citizens. Furthermore, the Rules recognise that disabled people have fewer opportunities for school and work, which they attribute to poor awareness and knowledge of disability issues and fear of disability. The implementation measures of the 22 Standard Rules for the Equalization of Opportunities for Persons with Disability (UN, 1994) provide relevant guidelines for policymakers and programme developers. In South Africa, the Reconstruction and Development Programme (RDP) and policies such as the White Paper on an Integrated National Disability Strategy (ODP, 1997) have attempted to highlight the need to target these vulnerable groups as a priority. All the rules recommend that governments of member states work in close

<sup>4</sup> As recorded in the policy: National monitoring and evaluation of disability programmes in the implementation of the Rules



collaboration and consultation with *Disabled People's Organisations*, whose role is further outlined in *Rule 18*. Public awareness (*Rule 1*) and health and rehabilitation services (*Rules 2 and 3*) need to be addressed to facilitate participation in other areas. The relevance of certain rules in the lives of disabled women is highlighted here.

A review by Stienstra *et al.*, (2002) found that CBR programmes have provided access to services (*Rules 2 and 3: health care and rehabilitation*), essential assistive devices and equipment (*Rule 4: Support systems*). Read (2000) notes that key transitional phases for disabled children have included identification of disability, accessing education (*Rule 6*) and moving from child to adult provision (*Rule 2, 3 and 4*). These phases may have relevance for women in this study who were born with their impairment or acquired their impairment as a child or who have a disabled child themselves, as personal and societal experience brings these different dimensions into interaction. In South African literature, the absence in integration of disability issues in women's health and development was noted. Even recent studies (Goosen and Klugman, 1996; Hoffman *et al.*, 1998) failed to integrate disability issues and concerns related to education (*Rule 6*), employment (*Rule 7*), parenting (*Rule 9*) and women's health (*Rule 2*) to name a few. There is a single chapter on disability (Mda *et al.*, 1996) in Goosen and Klugman's (1996) book on women's health, which segregates their issues from non-disabled women. Thus, there is a risk of the perception that disabled women do not experience the other health related problems or concerns of non-disabled women. Similarly, in a review of *SPEAK*, a protest magazine that gave a voice to women's issues during the struggle between 1982 –1997 (Meer, 1998), there were only two references to the needs of disabled women in any of the stories and issues that were raised in the area of work, the struggle, home and community. Women, generally, were expected to enjoy serving their families, to be submissive and loyal and support the men in the liberation struggle against the common enemy of apartheid, but it is not clear whether disabled women were included in this finding (Meer, 1998).

The importance of family life and the right of disabled women to have sexual relationships and intimate relationships extends to women being allowed to marry and raise a family (*Rule 9*). Considering family life, motherhood has been experienced and understood in diverse ways, reflecting the lives of different groups or social divisions. This literature review found that many authors on women, motherhood and mothering point out that disabled women's experiences are generally absent (Ingstad 2001; Read, 2000; Thomas, 1998). Many accounts of single parent motherhood have been documented (Morris, 1992), which may have relevance, as a large number of women in our study were single. Beresford (1995, in Read 2000:59) found that support from extended families was enormously important and an unfavourable reaction from a family member toward the disabled person could be very distressing. In a similar vein, Read (2000) quotes a study by Atkinson and Crawforth (1995) about the bullying and teasing faced by siblings of disabled children at schools because of their impairment.

Reviewing the experiences of sexuality, it was found that disabled women are more often denied the fundamental human experience of sexual relations, intimacy and parental roles than other women. Abu Habib (1997) researched the situation of disabled women in the Middle East. She found that although

gender-related issues were similar to issues of non-disabled and disabled women alike, impairment and disability acted to further increase the vulnerability of disabled women and reinforce their subordinate positions in Palestinian society. Negative perceptions restrict the life chances of women, leading to restricted or no educational opportunities for them. She found that the situation was worse for poor disabled women who incurred the most disadvantages as they had very few opportunities in life to look forward to. The danger is that “disability is seen as a ‘homogenous’ and ‘sexless’ issue that links to challenges of gender blind assumptions” (Abu Habib, 1997:79). A study of 31 disabled women by Nosek *et al.* (2003) found six thematic domains, namely, sense of self, relationships, barriers, including environmental and attitudinal barriers and emotional, physical and sexual abuse, sexuality information, health issues, and sexual functioning. The importance of involvement in family, school and community activities, and attitudinal and environmental barriers faced by women in achieving social inclusion was identified. In a follow up survey, Nosek *et al.*, (2003) identified the health promoting behaviours that are common for all women generally. They comment further:

The social environment in which women with disabilities live is primarily a hostile one, transmitting stereotypes that have existed for millennia, resulting in stigmatisation and exclusion (Nosek *et al.*, 2003: 1743).

The literature suggests that the role of religion (*Rule 12*) has been viewed as both positive and negative (Miles, 1995). In a positive light, religious organisations have provided significant support, as disabled people have been included in the activities of the organisation. Miles found that religion has been viewed negatively when the belief related to the cause is associated with sin and punishment from God. Despite this negativity, research shows that religious orientation has played a role in the lives of parents and caregivers as a coping strategy. A person’s spiritual belief system and philosophy of life was found to shape the meaning of disablement for each person (Selway and Ashman, 1998). Prayer, church attendance and specific religious beliefs are sources of support, giving hope and strength to the person. Selway and Ashman (1998) draw on Rozario’s study on the transpersonal aspect of religion and health that showed that individuals underwent a journey of inner transformation and growth, experiencing and integrating a deeper meaning, sense of self, wholeness and spirituality within their lives. This study hopes to discover whether community approaches to disability provide opportunities for DPOs and practitioners to explore these aspects of spirituality and religion in more depth as potential strategies for equalising opportunities.

Recent shifts in policies and approaches may mean some glimmer of hope for disabled people who have experienced extreme oppression and human rights abuses, globally and locally. The UN *Standard Rule 15 on legislation* indicates that Member States have a responsibility to create the legal basis for measures to achieve the objectives of full participation and equality for disabled people (UN, 1994). Farmer (2000) described how international agreements, laws, and policies do not necessarily ensure the protection of the physical integrity of disabled women who remain vulnerable to sexual abuse or other forms of exploitation. Nosek *et al.* (2003:1744) found that legislation had a positive effect at lowering exclusion by

reducing barriers to social integration and creating a social atmosphere that sees disability as a personal characteristic and not a reason for exclusion and stigmatisation.

While *Standard Rule 16: Economic policies* (UN, 1994) identifies the State's financial responsibility for national programmes and measures to create equal opportunities for disabled people, there has been little political commitment by the policymakers across the Ministries to see disability as a cross-cutting issue related to human rights (ODP, 1997). In a study of youth in Cape Town townships, Ramphela (2002) found that women living in poverty struggle to bring up children because of extreme material hardships, with negative consequences for their health and well-being. The importance of inclusive development for disabled adults has not been recognised and advocated in the same way as inclusive education (*Rule 6: Education*) for disabled children in South Africa (Department of Education, 2001). *Rule 21 on Technical and economic co-operation* suggests that Member States, both industrialised and developing, have the responsibility to co-operate in and take measures for the improvement of the living conditions of disabled people in developing countries. Read (2000) found that restricted financial resources limited the choices of families who have a disabled member and leave some in housing of very poor quality, especially taking into consideration additional needs of space and environmental adaptations.

There is consensus that the key ingredient for sustainability of CBR is the ownership and active participation of local DPOs in all aspects of programme planning, implementation and monitoring (Asindua, 2002; Rifkin and Kangere, 2002; Ndaziboneye, 2002; Kandyomunda *et al.*, 2002; WHO, 2003). *Rule 18: Organizations of persons with disabilities* calls for states to recognise the right of organisations of disabled people to represent themselves at national, regional and local levels (UN, 1994). In countries where DPOs have been active in the implementation of CBR (Ndaziboneye, 2002; O'Toole and McConkey, 1995; Rule, *et al.*, in press; Werner, 1992), CBR has been found to be an effective strategy for promoting the rights of disabled people. This success may be due to their understanding of disability as social oppression, which needs to be explored in this study. Research in South Africa has also showed that CBR programmes have been successful in increasing the confidence and skills of disabled people to contribute maximally to their family life (Dolan, Concha and Nyanti, 1995; Lorenzo and Cloete, 2004).

Member States of UN who ratified the Standard Rules are responsible for the establishment and strengthening of national co-ordinating committees (*Rule 17*), or similar bodies, to serve as a national focal point on disability matters across Ministries and sectors at national, provincial and local government level. Research on gender and disability in the Middle East highlighted that building capacity of individual disabled women failed to help the wider membership of the disabled women's organisation (Ramadan, 1997). It was found that engagement in women's issues and women's groups at all levels of organisation and government was essential. Such engagement would encourage dialogue and exploration of issues and ideas that would lead to inclusion of disabled women in human development and social change. Co-ordination of work could be closely linked to fostering international co-operation (*Rule 22*) concerning policies for the

equalisation of opportunities for disabled people. In addition, *Rule 19: Personnel training* focused on the State's responsibility to ensure the adequate training of personnel at all levels involved in the planning and provision of programmes and services concerning disabled people. Such measures would mean that the government and service providers would also recognise the advisory role of organisations of disabled people in decision-making on disability matters. The potential contribution that this study may offer to the field of health professional training in disability awareness has been discussed in the previous section. Information and research are critical areas for development.

In looking at human development in the South African context, Taylor (2000) has noted that poverty was characterised by unequal development in terms of infrastructural and administrative capacity, assets, and access to information, knowledge and opportunities. *Rule 13: Information and research* calls for member states to assume the ultimate responsibility for the collection and dissemination of information on the living conditions of disabled people. The rule seeks to promote comprehensive research on all aspects. Linked to this is another critical dimension of research on disability and CBR mentioned earlier is provided in *Rule 20: National monitoring and evaluation of disability programmes in the implementation of the Rules*. This rule identifies the member state's responsibility to ensure continuous monitoring and evaluation of the implementation of national programmes and services concerning the equalisation of opportunities for disabled people (UN, 1994). Monitoring and evaluation has been one of the weakest areas of CBR programmes in South Africa (Rule, *et al.*, in press). There has been very little publication and dissemination of the few evaluation studies that have been done (Hess, 2003). One of the reasons for this has been that research has not been demystified for programme managers and the staff and membership of projects. Institutions of higher education such as University of Cape Town could play a significant role in utilising their capacity, skills and resources to assist NGOs, DPOs and public health services to collaborate in developing monitoring and evaluation tools and plans. The challenge to practitioners from the different sectors would be to collect information related to indigenous knowledge and belief systems about disability, including strategies to minimise obstacles that affect the lives of disabled people, which have provided some ingenious ways of problem solving within resource-constrained environments. The findings from this research should be included in all relevant policymaking and national planning, as outlined in *Rule 14*.

The action of mobilising and organising disabled women in this study to participate in disability research intends to yield long-term benefits related to service delivery and community development through social transformation. Such action may contribute to sustainability of CBR programmes to equalise opportunities and facilitate social inclusion of disabled women in poverty alleviation and human development programmes.

## REFLECTIVE SUMMARY

Transforming the process of human development of disabled women needs to ensure that barriers related to deprivation and oppression are removed. The links between poverty, human development, community-based

rehabilitation and equal opportunities for disabled women have been explored. The literature acknowledges the absence of the integration of disability issues for women into mainstream policy development, research studies and the implementation of service delivery. The role of disability research in this regard was argued. The next chapter explores the process of discovering a suitable research methodology for the study with the disabled women in Khayelitsha and Nyanga communities in Cape Town.

University of Cape Town

## **Chapter 3**

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# **Exploring Participatory Action Research: A Suitable Methodology**

**Introduction**

**Adopting a qualitative research approach**

**Creating appropriate methodology**

**The influence of co-operative inquiry**

**Participatory action research**

**The influence of liberation education on the research design**

**The influence of Emancipatory Disability Research**

**Confirming the relevance of PAR for this study**

**Potential pitfalls of the PAR for this study**

**Reflective summary**

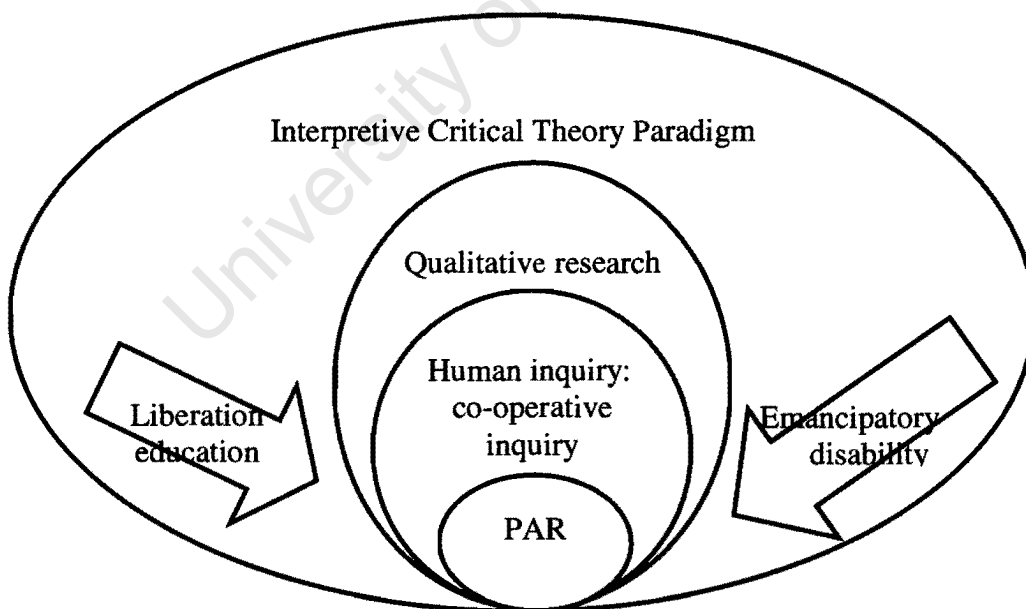


University of Cape Town

# Exploring Participatory Action Research: A Suitable Methodology

## INTRODUCTION

This chapter describes how the research paradigm was chosen. The chapter addresses four aspects related to methodology (see Figure 3). I describe the reasons for adopting a qualitative research approach within an interpretative, critical theory paradigm. Then I discuss the process of selecting an appropriate research methodology. In the process, we considered the conceptual framework of the human inquiry approach of participatory action research (PAR). The process also involved consideration of the influences of co-operative inquiry, liberation education, and lastly, emancipatory disability research. I assert the relevance of PAR as a methodology, guided by the research question and intention of the study. The chapter ends with the identification of the potential pitfalls of PAR for this study.



**Figure 3: Aspects considered in choosing a methodology**



## **ADOPTING A QUALITATIVE RESEARCH APPROACH**

We recognised that a naturalistic qualitative research approach would allow for a flexible yet in-depth inquiry (Lincoln, 1992). This approach allows for engagement and active involvement of the women in the research process, so that they would not become the objects of research, but to all intents and purposes, would guide the path that the research took. The research was carried out in the natural contexts of the women, the places where they live and interact (Lincoln, 1992).

Qualitative research has been described as “non quantitative methods that attempt to grasp phenomena in some holistic way or to understand a phenomenon within its own context” (Lincoln, 1992:376). It emphasises broad understanding and deep insight rather than presenting numbers. My intention was to capture through in-depth description the richness, texture and nuances of how the women experienced their development since becoming disabled (Lincoln, 1992). We hoped to explore the actions, beliefs, feelings, as well as the personal and social values of the women in their pursuit of equal opportunities for development. Inquiry models are known to “allow for the display and consideration of complex interactions” (Lincoln, 1992:378). Therefore, a naturalistic inquiry would enable an exploration of the multiple meanings that the women attached to their experiences of human development. Rubin and Rubin (1995) argue that qualitative research differs from the laws of physics, as it is not looking for principles that are true all the time and in all conditions. Rather, “the goal is understanding of specific circumstances, how and why things actually happen in a complex world” (Rubin and Rubin, 1995:38).

In the context of this study, truth and knowledge were therefore considered to be situational and conditional. The implications for this philosophy of research design were that I had to ensure that, firstly, the research methods elicited examples, narratives, histories, stories and explanations in order for me to gain some understanding of what participants had seen, heard or experienced. Secondly, what was heard could be distorted by the kind of relationship that existed between the participants and the researchers, both individually and within the group. Substantial attention, therefore, had to be paid to how participants perceived the research facilitators and each other and how these perceptions influenced what they were willing to share (Miller and Glasner, 1997). Thirdly, as a white, non-disabled woman researcher working cross-culturally, I had to manage a high degree of cross-cultural uncertainty. I worked with two research facilitators, who were both black and spoke Xhosa. I had to be self-confident, adaptable and willing to change direction in response to an emerging understanding during the analysis process, as there was minimal translation from Xhosa to English and vice versa during the data generation process. The research design had to allow for mistakes and recoveries, as well as curiosity and creative responses to emerging realities. We had to be prepared for “multiple possibilities” (Rubin and Rubin, 1995:41), since our preconceptions were challenged. Scarborough (1999:2) comments that the Truth and Reconciliation Commission (TRC) in South Africa broadened the meaning of “truth” as narrative, dialogue and healing truths, not only factual and objective truth. Narrative truth captured the record of people’s perceptions, stories, myths and experiences, to facilitate restoration of memory and humanity. Social or dialogue truth is the truth of experience that is established through interaction, discussion and debate. Victims presenting at the TRC

told a story of past suffering, without needing supporting documentation or other evidence or being cross-examined.

In addition, the influence of critical theorists provided a means to address the alienation that often occurs in social research (Fine *et al.*, 2000; Kincheloe and McClaren, 2000; Olesen, 2000). Social research on disability has been criticised for the alienation of disabled people – from the product of research, the process itself, and other research subjects and from the researching self. Adopting critical theory to a qualitative approach to disability research would promote the inclusive nature of the data collection processes; seeing the disabled person as the expert, and seeing the organisation of society as the root cause of disablement. The research process would address and be cognisant of segregation, inequality, poverty, discrimination and oppression experienced by the women. Oliver (1997) argues that disabled people see research largely as a violation of their experience and as irrelevant to their needs, as it fails to improve the material circumstances and quality of life.

Stubbs (1999) advocates that rigorous engagement in disability research has the potential to contribute immensely to the major issues of development, research and social exclusion in the broader social development arena. Such engagement would lead to “deeper insight, personal transformation and research that is emancipatory and not exploitative” (Stubbs, 1999:258). Therefore, issues of resources and power would be held in constant focus when selecting an appropriate research methodology.

## **CREATING AN APPROPRIATE METHODOLOGY**

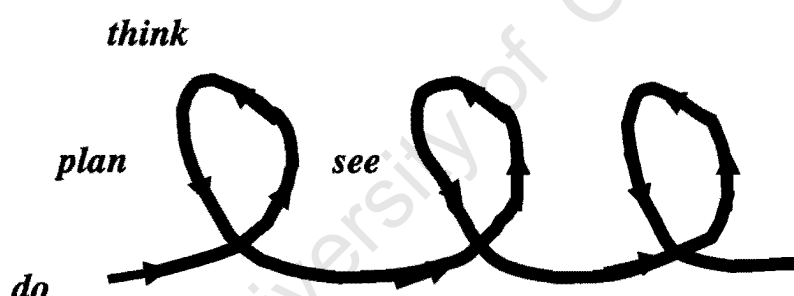
Stubbs (1999) proposes that careful consideration needs to be given to the planning and decision-making process in preparation for a study. This process would entail identifying the values and reasons behind the research, the choice of companions and an agreement on the etiquette and behaviour of research partners. An important decision about what to do with the data, who owns it, keeps it (when, where and how) as part of analysis needed to be considered thoughtfully and a decision agreed to early on.

As facilitators of disability research, we intended to be more than just extractors of information. Through attentive, integral and rigorous approaches to research, we aimed to strive for results that would advance greater social justice and emancipation for all. Stubbs (1999) advocates that research has the potential to bring the two ends of the development continuum from the personal to the global together. However, we decided to focus our attention on the personal and local aspects of development, while taking cognizance of global debates in the literature. Thus in the process of discovering a suitable research methodology, we considered two approaches in human inquiry (Reason, 1994), namely, co-operative inquiry and participatory action research (PAR).

## The influence of co-operative inquiry

In exploring different ways of human inquiry, the research facilitators considered whether co-operative inquiry would be more suitable as a methodology. Co-operative inquiry focuses on the assumption that people are self-determining (Reason, 1994). This aspect appealed to us since self-determination is one of the core values informing the philosophy of the Disability Rights Movement. As the study would be related to the experience of the women in development, it appeared that this approach might be suitable to engage the voices of disabled women. The purpose of co-operative inquiry would be to provide a means for participants from the different experiences to develop a deeper understanding of the possibilities of collaboration, which could influence the achievements of equal opportunities for disabled women.

Co-operative inquiry moves through four stages of action-reflection cycles. There are four steps with each cycle, namely, doing, seeing, thinking or reflecting and planning (see Figure 4). The participants are actively involved with each other in the context of the study (Reason, 1994). They identify the main questions and actions that the study would seek to address. Towards the end of an inquiry the group may be able to develop a theory or description of its practice that remains rooted in their experience together. The primary instrument of research is the self-directing person within a community of inquiry as the “source of knowing” (Reason, 1994:41).



**Figure 4: Steps in the action-learning cycle**

Much as the potential for adopting this methodology was considered, it proved difficult to meet the criteria of co-operative inquiry. There was still a need to build capacity and demystify the research process for the women and CRWs to take active ownership and control of the process. Co-operative inquiry would take significantly more time and resources to develop and establish full, authentic co-operation, as participants were at different levels of competence in research. Furthermore literacy levels amongst the women differed. An approach that allowed more dialogue and an oral medium of participation was considered. Thus, the possibility of adopting a PAR emerged as a better option.

## Participatory action research

Participatory action research emphasises the emergent processes of collaboration and dialogue that motivate, empower, increase self-esteem and develop community solidarity amongst poor people who have been deprived, oppressed and marginalised (Reason, 1994). Two objectives of PAR that were particularly relevant for the purpose and aligned with the requirements of the methodology for this study were, firstly, to produce knowledge and action directly useful to the women. This meant a combination of research, adult education and socio-political actions. The second objective was consciousness raising or conscientisation to empower people through the process of constructing and using their own knowledge. In this way, they would learn to “see through” the ways in which established interests monopolise the production and use of knowledge for their own benefits (Reason, 1994).

De Koning and Martin (1996) explain how PAR goes beyond documenting local people’s needs and perspectives so that it becomes a process of knowledge production. They advocate that the strength of PAR is its potential to help those who are perceived as marginalised and deprived of opportunities for development, to gain self-confidence and pride in their ability to contribute towards their communities again. Participants would also recognise their potential to generate knowledge for the training of students who would be the future service providers and practitioners engaged in working to meet the health, disability and development needs of communities. We were further convinced by the findings of De Koning and Martin (1996) who explained how professionals and researchers would be able to empathise with the problems people face, leading to more respect for their insights and knowledge. We agreed with Werner (1995) that while poverty is the most disabling condition, it is often difficult to overcome because people lack the confidence to make a change. Facilitators and practitioners need to learn to trust the potential of people and their capabilities to meet their own needs. We took heed of Taylor and Conradie (1997:14) who caution that PAR can be a tool for development only if it enables the participants to go beyond a critical analysis of their situation and when it leads to planned action:

Given the rapidly changing context in South Africa and the popular aspirations of people at the lowest socio-economic levels, [PAR] does provide a basis through which those concerned with human development can engage in a mutually beneficial and critical process of consensus building as opposed to the standard research and researched (subject-object) dichotomy.

PAR facilitates the exploration of the complex relations between silencing, silence and voice (Brinton Lykes, 1997). PAR helps research participants to move beyond a parochial worldview and culture of silence towards the creation of knowledge systems based on their needs and lived experience. Such a shift happens as the participants move beyond the adoption of a scientific or technical view imported from the dominant culture. As Reason (1994) points out, the research participants have a role in setting the agendas, participating in data gathering and analysis and controlling the use of outcomes. Willms (1997:7) supports such participation when he talks about a broader interpretation of research. He explains it as “a process of rediscovering and

recreating personal and social realities". We were encouraged by Willms' optimism in the ability of research to achieve meaningful social change when he goes on to equate PAR with a journey in which there is movement "from the way things are to the way things could be" (Willms 1997:8). In response to criticism of PAR, Stone (1997) concludes from her experience in China that PAR has potential to facilitate emancipation. Therefore, the methodology for this study was strongly influenced by liberation education theory adopted from Freire (Hope and Timmel, 1995; Taylor *et al.*, 1998), and emancipatory research theory (Oliver, 1992, 1997).

### **The influence of liberation education on research design**

Freire's approach of conscientisation and radical transformation (Hope and Timmel, 1995) has had a substantial influence on my practice, teaching and research. The approach enables a facilitator to work with a group of adults from impoverished and oppressed circumstances in a way that liberates rather than domesticates them, as they engage in critical thinking about the social and human values that inform their projects. The facilitator listens for generative themes, which indicate relevant issues within people's lives about which they feel strongly. Freire believed that there was a link between emotion and motivation: what people felt strongly about they would act on. Groups are often criticised for lack of motivation, which may more likely be apathy and powerlessness as a result of being repeatedly blocked in their attempts to make a change. Facilitators need to tap into the natural energy of individuals and groups through astute listening, constant dialogue, reflection and identifying actions:

Freire recognised that emotions play a crucial role in transformation. Feelings are facts. Only by starting with the issues that the community have strong feelings [about] hope, fear, worry, anger, joy, sorrow – and bringing these to the surface, will we break through the deadly sense of apathy and powerlessness which paralyses the poor in many places (Hope and Timmel, 1995:16).

Generative themes are posed to the group in the form of "codes" so that they are able to engage in dialogue to discover the root causes of the problems and how these issues affect their lives. The dialogue recognises that both facilitators and participants are simultaneously learners and teachers. There is a sense of mutual respect for each other, which tends to mitigate the inevitable power imbalance between the 'researched' and the 'researcher'. The dialogue leads to an action-reflection cycle as participants identify actions they can take towards social change by reflecting on lessons learnt. According to Freire (in Hope and Timmel, 1995:16) such an intense and in-depth process of reflection and action to tackle the root causes of a problem may lead to radical ("root") transformation at all levels of society as:

There is new awareness now that on all the major problems that face the modern world, no experts have all the answers ... we need to draw on the insights of all who are concerned as we search for solutions.

The action learning approach incorporates the principles of Freire and has been used successfully with oppressed groups (Taylor *et al.*, 1998). Action learning is based on the assumption that people learn from experience. The approach enables individual participants to reflect on their experiences and actions in such a way that the whole group learns from them and are enabled to extract lessons to ensure sustainability of individual and collective efforts of action-reflection. They comment that finding the right question was the most important place to start in the process of learning, which would be embedded within PAR.

### **The influence of Emancipatory Disability Research (EDR)**

Critiques of much research on disability have been grounded in experiences of oppression, perpetuation of the marginalisation of disabled people, systematic denial of human rights, eugenics, justifying segregationist policies, personal accounts of alienation, imposed passivity and betrayal (Barnes and Mercer, 1997; Stone and Priestley, 1996). The theoretical underpinning of human inquiry (Reason, 1994) and emancipatory disability research (Oliver, 1992; 1997) is that knowledge is a source of power. Reason (1994) suggests that we need to “hold lightly” the framework so as to notice how practice does or does not conform to the original ideas. It involves practical knowledge on how (and how not) to engage in appropriate action, to bracket off the starting idea and to exercise relevant discrimination. Emancipatory disability research raises the question about whether those struggling for political rights or resources need to bother about research in the first place. Some disabled people have viewed academic research as oppressive, as it only benefits the researchers and may even do harm to the disabled person. In EDR, research hierarchies where research has been built upon the privilege and power of non-disabled people would be reversed.

Emancipatory disability research (EDR) is a new paradigm for social research (Oliver, 1992). EDR has gained from feminist, anti-racist and development research. A critical theory of the materialist approach enables oppressed groups to emancipate themselves. It offers the possibility of creating alternative worlds through a process of struggle towards a vision of a better world and achieved through political action. Research as politics rather than research as science (discovering the truth about the world) is radically different, as it encompasses transition. EDR provides a new methodology to fight the social oppression of disabled people, by placing the problem within a patriarchal, racist and disablist society rather than the body (Stone and Priestley, 1996). The approach seeks to address power inherent in the social and material relations and discusses in more depth later in the chapter. Oliver (1997) defined emancipatory disability research as a new paradigm to facilitate a “politics of the possible” by confronting social oppression at whatever level it occurs. There is a need to recognise and confront power, which structures the social relations of research production as a central feature of the paradigm.

In considering an epistemology for the study, we choose the social model of disability within which disability is understood as a social relationship (Thomas, 2004), created by a disabling environment and disabling attitudes. Disability is seen as socially constructed, culturally produced and a form of structural oppression (Barnes and Mercer, 2004). Stone and Priestley (1996) have explored the issues of oppressive

theoretical paradigms and social relations in researching disability as experienced by disabled people. They maintain that:

the priorities of disability researchers must be the adoption of a social model of disablement, an overt political commitment to the development of the disabled people's movement, the use of non-exploitative research methods and a commitment to research which is widely disseminated for use against oppression (Stone and Priestley, 1996:15).

One principle looked at "surrendering objectivity". Disability researchers need to commit both to a social analysis of disablement and to the development of the disabled people's movement. Surrendering objectivity necessitates that the researcher acknowledges that claims to "detachment" and "objectivity" in a context of oppression are flawed (Hunt 1981, in Stone and Priestley, 1996). Instead, researchers share their vulnerabilities as well as raising the capacity for action and nurturing the strength to elevate the level of the disabled people's struggles. The researcher needs to engage in and with the lives of the researched, by making a commitment to the Disability Rights Movement as a social movement (Stone and Priestley, 1996; Oliver, 1997). One's role may be to assist the group's own self-analysis, as well as record the group processes in a critical way (Touraine, 1981 Stone and Priestley, 1996).

The challenge in disability research is to balance the twin requirements of political action and academic rigour. Committed research provides results that will benefit disabled people and their movements. We would attempt to navigate the tensions between oppressed and oppressor (Stone, 1997) by seeking to understand both the phenomenon of disablement and the experience of the women in a way that would ensure our accountability to them. For Priestley (1997), the challenge was one of equalising power and not devolving it. The study would need to be enabling for all involved. From experience, I was aware that the women might agree to participate in the research in order to please me (as a white researcher) because of the history of oppression in South Africa. This concern was addressed by bringing on board two fellow research facilitators who were both Xhosa-speaking.

This study aimed to focus on the micro-level of understanding the oppression of the women and their needs, so as to contribute to meaningful social change. Stone and Priestley (1996) identified "personalizing the political and politicising the personal" as a principle of EDR, as it explores the importance of differences in the personal experiences of impairment and disability (French, 1993, in Stone and Priestley, 1996; Thomas, 1998; 2004) and the primary relevance of such experiences as research data (Morris, 1998). Morris (1998), and more recently Thomas (2004) and Reeves (2004), argue for seeing the personal as political and giving voice to such subjective experiences, so as to assert the value of the lives of the women. As a disabled woman herself, Morris feels that to deny the personal experience is to collude in their oppression. She states that images of disadvantage must be consistently challenged through EDR, as they are such an important part of the experience of oppression. Thus the study would present the subjective realities of individual women as a way of recognising both commonality and difference in the experience of impairment and

disablement. As the stories of the women would be shared, each woman would be challenged or supported by the research facilitators where necessary. Such actions could lead to collective change at an individual, family and community level for the women. As such, the PAR study with the women would move beyond the knowing of individual realities to include collective realities, while researchers also considered both the commonality and diversity of the experience amongst disabled people. Oral tradition in the early stages of collective study by oppressed groups is important (Morris, 1991, in Stone and Priestley, 1996). The oral tradition is one that is familiar to the participants in this study.

EDR is considered as an activity within a social context. EDR challenges the existing disempowerment so as not to reinforce existing feelings of passivity or exclusion on the part of 'the researched'. As research facilitators we were willing to put our skills and experience at the disposal of the women, as a resource. However, Oliver (1997) comments that 'doing' EDR may be misleading. The real issue for Oliver is about the role of research in the process of emancipation. In other words, as the research facilitators, we would need to engage with those who were seeking to emancipate themselves. Therefore, our research could only be judged emancipatory afterwards. Stone and Priestley (1996:704) are clear that:

Only when disabled people and their organizations are at the apex of the research hierarchy (and this includes control of financing of research) can research be deemed emancipatory.

Revising the social relations of research explores the way research is actually carried out. The relations refer to the consultation by and with organisations of disabled people that have positive policy outcomes leading to social change (Barnes and Mercer, 1997). It is about the demystification of the ideological structures within which power relations are located (Oliver, 1992; 1997). As such, the research facilitators would focus on the way women were able to engage in different societal structures (such as civic organisations and transport systems), rather than on the specific impairments of individuals. We would be committed to maximizing participation in all research processes, within the constraints already mentioned, as part of the wider processes of education and politics. The research agenda focuses on the disablism engrained in the consciousness of individuals and in the institutionalised practices of what is ultimately a disabilist society.

The research facilitators decided to use the three criteria identified by Oliver (1997) as the yardstick for measuring emancipation through PAR, namely, reciprocity, gain and empowerment. Our decision to use PAR was enriched by the conceptual frameworks described above.



## **CONFIRMING THE RELEVANCE OF PAR FOR THIS STUDY**

Eventually, we came full circle to confirm our intention to use PAR as the methodology of choice for guiding the research process with the women in Khayelitsha. However, the methodology was considered eclectic as it incorporated PAR from an interpretive critical paradigm, which views disability as a social problem, together with critical theory encompassed in the principles of the emancipatory disability research paradigm, which sees disability as a political problem (Oliver, 1997). It was a lengthy process of dialogue and debate, so as to ensure that women would benefit as much as possible from the research. My experience and training gave me confidence in the potential of people to participate and to commit to taking action, if power dynamics are continuously reflected on. PAR allowed for such reflection.

The value of using PAR was that it would allow an action learning approach as described earlier (see Figure 4). In this way, the women were able to be actively involved in and reflect on their own development process. They would have the opportunity to develop increased awareness and capacity for learning about themselves and their development. Using action learning in PAR would ensure relevance by identifying what the women felt strongly about. This would lead to problem-posing, dialogue and reflection to gather information and engage in action for meaningful social change (Hope and Timmel, 1995).

A PAR process would also allow for the use of diverse methods derived from vernacular and oral traditions, e.g. storytelling, poems, song, drama, dancing, and group discussions. PAR would provide an opportunity for the women to take more control over their own lives. The process emphasises the political aspects of knowledge production about disability, as new levels of understanding and political competence in disability issues emerge (Reason, 1994). PAR would provide data with which to make decisions and a raised awareness of the external forces affecting decisions. PAR would seek to establish equality between the research facilitators and the participants, as it would allow simultaneous development of self-confidence and capacity amongst the women themselves.

## **POTENTIAL PITFALLS OF THE PAR FOR THIS STUDY**

Although the interpretive, critical paradigm in qualitative research contends that all knowledge is socially constructed within a particular context, Oliver (2000) cautions that such research does not automatically change the social situation for disabled people if the social relations of research production remain unaltered. However, it needs to be noted that incorporating the action learning approach engages participants in a critical analysis of their situations and facilitates identification of root causes of oppression and identification of action.

Thus, PAR would have to be robust enough to enable identification, qualification and removal of disabling barriers. Time and resource constraints, as well as cultural diversity, meant that no guarantee could be given of removing barriers identified through the research. Such criticism was identified by Bury (1996, in Zarb,

1997), who suggests that research using the social model of disability has failed to provide an alternative or adequate approach to the diverse views and experiences of disabled people in different contexts, as there is a lack of conceptual clarity and methodology. The philosophy of service delivery is based on primary health care (PHC) principles and human rights, but the reality of resource constraints and the absence of reorientation of existing practitioners in public health services may be a hindrance. The different approaches of NGOs, disabled people's organisations and public service providers will also present a challenge to implementation.

Zarb (1997) described the practical issues that he addressed in a participatory research project focused on identifying disabling barriers that lead to the exclusion of disabled people in the United Kingdom. He looked at how institutional social and economic structures contribute to forms of exclusion experienced by disabled people. He mentioned that it is important to consider the social and material relations of research production (as mentioned earlier) in participatory research and how these relations impact on the way disabled people are involved, in order to achieve the transformatory potential of this type of research. We need to maintain a critical awareness of how work as researchers can contribute to or challenge the particular forms of exclusion being researched.

## **REFLECTIVE SUMMARY**

The chapter presented the reasons for adopting a qualitative research approach to the study, as an understanding of the lived experience of disabled women with the context of their everyday lives was sought. The transformative potential of disability research needed to extend beyond individuals to confront the social structures of oppression. In the process of creating a relevant methodology, the influences of co-operative inquiry, liberation education and emancipatory disability research were considered. Participatory action research was chosen, as it offered opportunities for addressing power dynamics, and producing knowledge and actions through collaborative efforts of critical stakeholders. An action-learning approach ensured relevance, as it identified generative themes through active listening and allowed problem-posing and dialogue to create action plans for social change by the women themselves. The chapter closed with the potential pitfalls of PAR that the researchers had to be aware of.

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## Chapter 4

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# Methods to Generate Data: Research Design

### Introduction

- Research facilitators
- Research participants

### Phases of the study

#### Data Production

- Data generation methods
  - Story telling groups
  - Narrative action reflection workshops
    - Data triggers
    - Process of workshops
    - Workshop preparation and planning
    - Data capturing
  - Reflective journaling

#### Data Analysis

#### Verification of authenticity of data

- Credibility
- Transferability
- Dependability
- Conformability

#### Bracketing assumptions

#### Ethical considerations

#### Reflective summary



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# Methods to Generate Data: Research Design

## INTRODUCTION

The previous chapter described how the methodology for the study evolved. The design used to operationalise PAR will be described in this chapter. I begin with an account of the research facilitators and participants. This is followed by a description of the data production process, which comprises data generation methods, data analysis and data interpretation. The process of verifying the authenticity of the data involved four aspects, which are described. The ethical considerations are outlined. A summary of the phases of the study is given.

The study unfolded organically as an exploratory initiative, in response to the felt and expressed needs of the women who participated in the initial storytelling workshops. PAR methodology allowed for a flexible approach, responsive to emergent issues as the study progressed, so that the study remained relevant. Bailey (1997) comments that qualitative data are rich and powerful with the potential for revealing complexity. This aspect resonated with the purpose of the study. The factors that impact on the development of people are complex. Thus the challenge was to identify research methods that would generate data that reflected the 'true' state of their human experience of development (Polit and Hungler, 1997; Rubin and Rubin, 1995). Therefore, an understanding of the research partners and participants that emanated from their own reflections was essential in order to generate data that could be considered truthful.

## Research facilitators

There were three research facilitators who guided the research process. Two of the facilitators were staff members from the Division of Occupational Therapy at UCT. I was a senior lecturer in community-based rehabilitation and disability studies (see Prologue). Peliwe, a research assistant, was a recent graduate in occupational therapy. I was very fortunate to be the supervisor of Peliwe when she was a fourth year OT student at SACLA for a six-week practical placement. At that stage we were planning how to take the research forward. She was Xhosa-speaking, and so very at home in this placement. On graduating, she accepted a post as a research assistant in two research studies that the OT department were involved in with SACLA at the time. She was an asset to the study with her enthusiasm and wonderful sense of humour. She was not shy in giving her perspective and opinion. Her engaging interactions with the participants combined with professional expertise, enhanced the collaboration during the analysis process.

Marjorie, who is a disabled woman and ex-nurse and presently chairperson for the Disabled Women's Development Programme of DPSA, was the third facilitator. I was always struck by Marjorie's quiet but strong presence, no matter she was interacting with. I have known Marjorie since 1996, when we were planning a workshop between DPOs and NGOs in the local health districts to look at service delivery and development projects. In the workshops, she was always able to strike a balance between nurturing and confronting the women. She was a competent peer counsellor and grew in her role as a researcher. The mutual learning during the different processes of analysis with the women and research facilitators enhanced her skills and confidence to explore meanings, offer tentative interpretations and debating differences across cultures. She often played a mentoring role for many professionals in the field. With Marjorie, we were able to laugh and cry, argue and debate on a number of issues besides disability.

### ***Community entry and getting started***

As research facilitators, we were able to gain entry and establish rapport and develop trust with the participants (Meulenberg-Buskens, 1996; Polit and Hungler, 1997). I had worked with the two partner organisations for three years prior to the commencement of the research (see prologue and Chapter One). I was also involved with the Community Disability Entrepreneurship Project (CoDEP)<sup>5</sup> groups of SACLA, which allowed opportunities to observe relatively unobtrusively without participants feeling intimidated. I supervised fourth year occupational therapy students who were placed at SACLA three times a year for six-week blocks as part of their service learning practice. This afforded an opportunity to observe the development of the women through the interactions, insights and perspectives of the students. As mentioned earlier, Peliwe was an undergraduate student for six weeks before joining the project for a period of fifteen months the following year. Knowing the Xhosa language was a great asset for her, as she was able to understand the emotional undertones of groups as well as what members discussed informally. She often felt challenged by being so much younger than the women and it was sometimes deemed inappropriate for her to confront the women directly, as culturally older women usually provide guidance. Peliwe's role as a research assistant became pivotal to help the women with key issues related to accessing resources, such as transport, marketing, and a place to work. She helped with problem solving, planning and organisation to promote action-reflection between the NAR workshops, to enable the women to become catalysts in accessing resources. Fortunately Marjorie, as the other research facilitator, was respected because she was older and had disability experience herself. Marjorie was known to many of the women as she lived in the adjacent township and was provincial chair for DPSA's Disabled Women's Development Programme. Furthermore, both organisations had requested that I facilitate further development in the focus area of research. So, to some degree, I had gained an awareness of the social world of the women before the commencement of the study.

Thus the three research facilitators formed a core team who were responsible for the design and management of the study. One of the community rehabilitation worker co-ordinators from SACLA, was responsible for the logistical arrangements and also participated in some of the monthly planning and consultative dialogue

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<sup>5</sup> See Introduction for description of this project

meetings. Ten of the CRWs participated in the monthly workshops. The venues for the workshops rotated between two community halls and a church hall in five areas from which the women came. The CRW co-ordinator and CRWs did all the booking of venues and transport arrangements. A CRW made a three-legged African pot from clay to represent her understanding of the partnership in PAR between CRWs, women and UCT researchers (see opening quote of thesis). The symbol was a constant reminder of the need to be vigilant of power dynamics and to maintain a balance in power (see Figure 5 for the research process).

## Research participants

The research population included all disabled women who had participated in activities of the two organisations, namely SACLA and DPSA. Unfortunately, no database has been kept at SACLA or DPSA on the number of disabled women in these two districts. A survey of Western Cape indicates a prevalence rate of 3.8 % of African population who reported having an impairment. The rate for urban areas in the Western Cape was 3.9% and 3.3% rurally (Schneider *et al.*, 1999). The women who were involved in the PAR study lived in wooden shacks in the peri-urban areas of Khayelitsha and Brown's Farm on the outskirts of Cape Town, South Africa. Purposive sampling (McMillan and Schumacher, 2001) using the snowballing technique was carried out. The research facilitators were constantly aware of creating a power dynamic linked to the tensions of exclusion and inclusion (Zarb, 1997). Therefore, any woman who met the following criteria was invited to attend and participate in the workshops:



A CRW making a clay pot to depict the partners in the PAR study

- Age between 18–50 years, as these are seen as economically productive years, and women would potentially provide information rich data.
- Resident in the informal settlements (squatter camps) of Khayelitsha and Brown's Farm.
- Known by SACLA or DPSA (they had participated in current or past activities of either organisation).
- Impairment status: there were no exclusions related to any impairment category as a process of snowballing occurred. Participants had been referred to SACLA or DPSA by different routes, including self-referral. In this way, their status as "disabled" was based on self-disclosure, i.e. they identified with an experience of disability.
- Economic status: no one was excluded on the basis of income, access to social security or employment.



In 1998 the women participated in storytelling groups on their experience of disability. There were 45 women who participated in the initial storytelling groups. In 1999 the women and the CRWs indicated that they would like to continue the process of exploring the barriers and strategies that had been identified in the stories. Women were free to participate at a level they felt comfortable, and to enter or exit as they desired. Approximately 180 women participated in the study over the two and a half year period of data generation. Workshop dates were set on a monthly basis for the third Thursday of every month. We did not follow up those women who chose not to continue participating in the study, due to our resource constraints. Thus, a limitation of the sampling approach was the potential bias of women of a certain age or impairment leading to over- or under-representation. However, there was no intention to generalise the results (see page 69).

In sharing their stories, not all women revealed the details of their impairment, and records at SACLA were not always accurate or complete. The major causes of impairment that were given were classified in three overlapping groups, namely, medical conditions, such as congenital deformities epilepsy or vascular diseases, road traffic injuries and trauma from violence and abuse. The impairment happened across the life cycle, with some women being disabled since childhood, some women as a young person, adult or as an elderly person.

Using the social model of disability as a framework, the focus of the study was on the women's perceptions of 'disability as a social barrier', so as to understand 'disabling environments' and the meaning of events. Thus, the researcher facilitators did not deem the details of impairment as essential for this study. No quantitative data related to the women was collected. None of the workshops focused on any one impairment group as such. However, women were free to discuss any consequences of their impairments in the workshops as part of their stories.

## PHASES OF THE STUDY

Stubbs (1999:268) shares advice and encouragement from Chambers: "start, stumble and self correct". This describes well the process we seemed to go through. There were four phases of the research (see Figure 5 and Appendix 2 for specific details)

### Phase 1: Setting the scene for PAR

Phase I covered a period of nine months: three months of preparation and planning of storytelling groups, followed by five storytelling groups, which were done over a period



Women listen to each other's stories

of six months (June-December). CRWs in five areas organised the women in their area to come together for a 3-hour group. Attendance at the workshops was voluntary. There were 8-10 women in each group that followed a similar process. Each woman drew a picture to use in telling her story about experiences of disability and development to the whole group. The stories were analysed to identify factors that hindered and fostered development.

## Phase 2: Planning to take PAR further

In March 1999 women voiced a need through their respective CRWs to meet again. Five narrative action-reflection workshops for planning followed and took place every second month (May 1999–February 2000). There were five broad domains of action that emerged from the planning:

- Publications of stories.
- Getting business training and entrepreneurial skills development.
- Securing accessible public transport.
- Raising public awareness.
- Organising as a group.



Women explain clay sculptures they made to show changes

The stories on actions and changes in Chapter Six report on these domains of action.

## Phase 3: Implementation of actions

In January 2000 the research facilitators met to review the progress thus far and to plan for the year. There was a request from the women that we meet monthly, which we agreed to do. The March, April, and May 2000 workshops focused on the themes of identity and approaches to disability at an individual, family and community level. In the March workshop we looked at identity at an individual level. In order to answer the question: "How do you know yourself as a disabled person?" women had to find an object from the environment that symbolised their identity since acquiring their impairment. In the April and May workshops the focus was on the family and community contexts, to explore the nature of 'carrying a load' from the storytelling groups in greater depth. The group was divided into small groups of six women. The newcomers were grouped together and the CRWs also formed a group of their own. The process involved using two pictures as "triggers". One showed a woman who was burdened by the load she was carrying and the other showed a picture of a woman happy and smiling and coping with the load she was carrying (see appendix 3 for pictures and sample of responses). Each person was asked to describe what she saw happening in the



picture and steps for analysis of the code were given (see appendix 4). The women applied what they saw in the picture to their own experience of the load in their family and how the load stopped and/or fostered their development. Two questions were posed related to the objectives of the study and were discussed in small groups. At the end of the report back, each group wrote a song summarising their responses to what had been shared in the groups. These songs were shared at the end of the workshop with each group going onto the stage.

The monthly NAR workshops from June to November 2000 focused on aspects of skills development, so as to build a network of support and shared skills that would begin to remove the barriers identified and strengthen strategies used for social integration, economic empowerment and employment, and political development. The workshops were informed by, and informed, the projects of both SACLA Health Project and DPSA through a close working relationship. The ongoing process involved completing a plan of action at each monthly workshop, where the groups identified critical issues to learn from, namely:

- What did we plan to do? When? How?
- What did we achieve? What problems or difficulties did we see?
- What changes did we see? What did we learn?
- What is our next step? Who is going to do what? When? How?

In the November 2000 workshop, as a way of consolidating the second year and celebrating what had happened during the skills development phase, participants were asked to find a partner who was someone she did not know well. Each person had an opportunity to share so as to identify how much the women had gained and what needs still had to be addressed. Report back was done in pairs to the whole group. It needs to be noted that the facilitators had not prepared a systematic review, but rather used an open-ended approach to determine what the women valued from the process. Prompts or probe were not provided, so in some instances, there is no indication whether there were improvements in certain areas.

#### **Phase 4: Dissemination of findings**

This phase involved various activities related to dissemination of findings, such as the preparation and presentation of three seminars on the research process that took place at the beginning of 2001, as well as conference presentations (see appendix for example of posters made; see references for details of conferences).



**The facilitators and a disabled woman present a seminar**

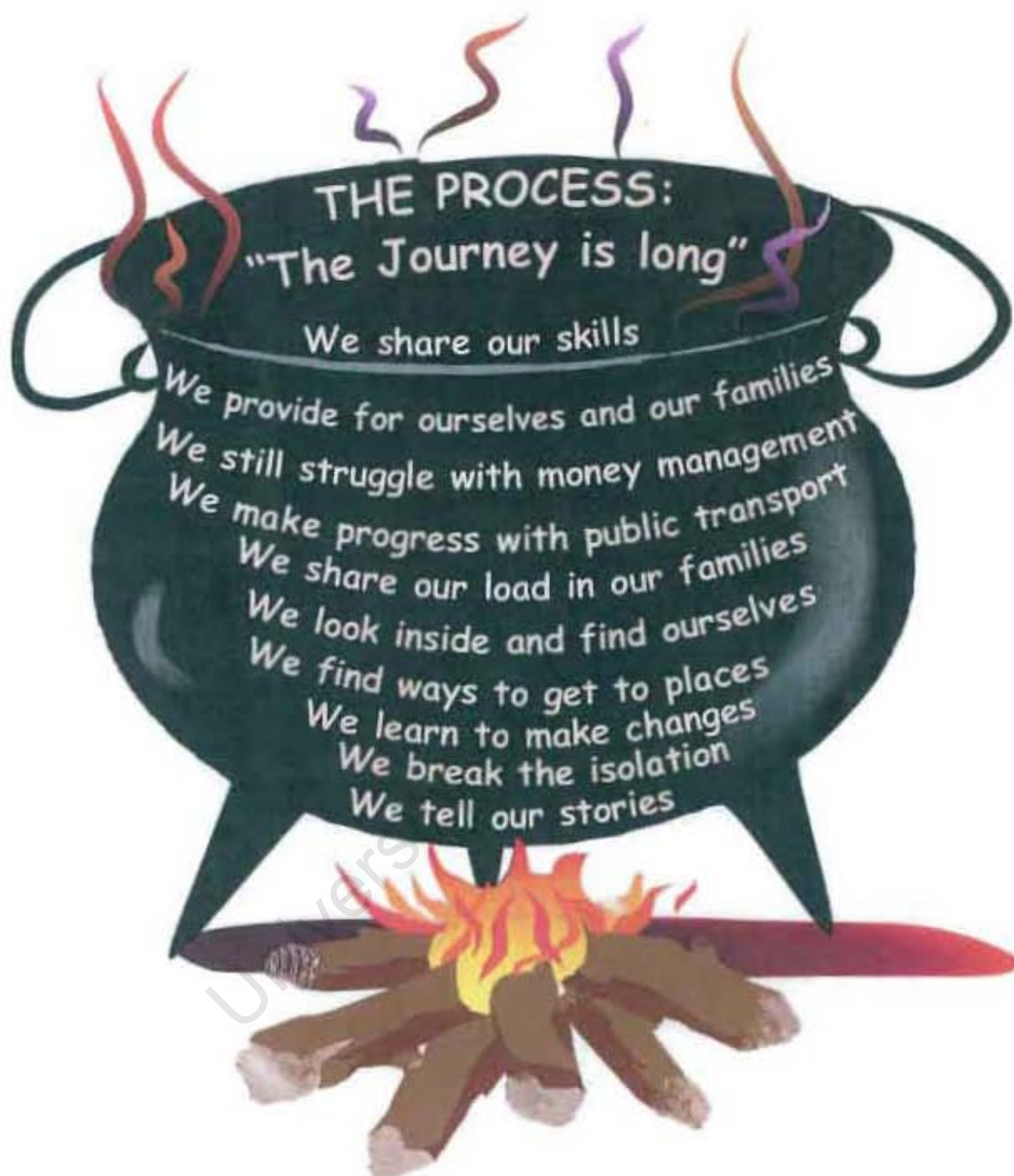


Figure 5.  
Research process

## DATA PRODUCTION

Data production would be located within the epistemological framework of the social model of disability, as we intended to identify barriers and strategies to equal opportunities for human development at an individual and societal level. Individual barriers could include those related to self-esteem and psychological components, and not just the physical impairment (Thomas, 2004; Reeves, 2004). Their experiences were explored and analysed for the changes that occurred from participation during the workshops, as well as their actions and different opportunities arising out of the workshops. Figure 6 is a graphic presentation of the research process that illustrates the aspects of data production.

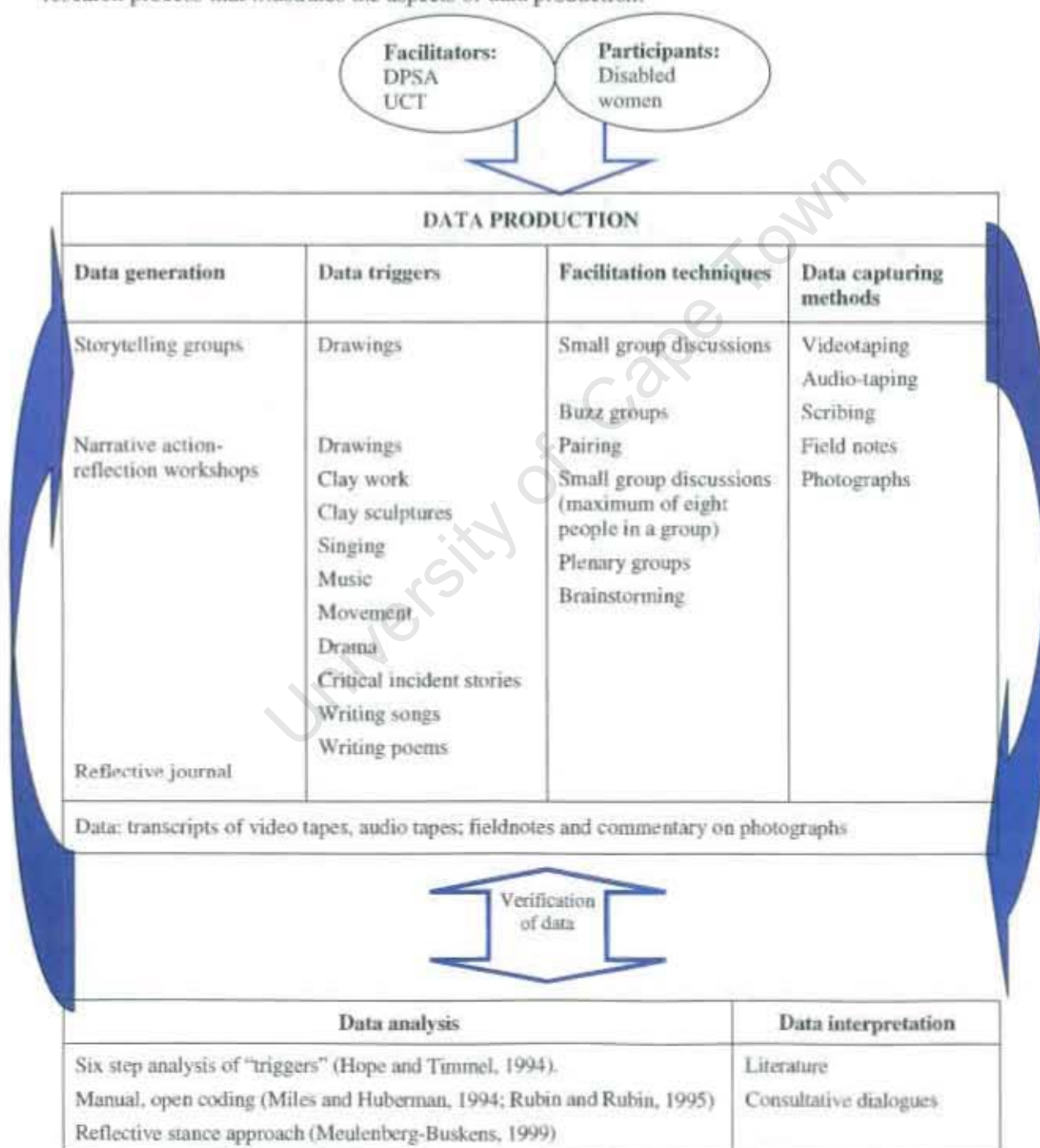


Figure 6: Data production process



## Data generation methods

The choice of data generation methods was guided by the research questions, which informed the choice of PAR as the methodology, as well as the identification of key themes and issues from workshops that required further exploration (Lincoln, 1992). Stubbs (1999:258) maintains that methods used in disability research as tools for data generation should be non-confrontational so as to help demystify the research process as an elitist activity done by academic "experts". Polit and Hungler (1997) comment that data generation is a time-consuming activity in research. It can stimulate creative and critical thinking and provide room for difference in opinion. The research facilitators were aware that there was a need to make a commitment to create a space where the women could give voice to their experiences, together with a commitment to fight the system that creates oppression. We hoped that the research would enable the women to speak authoritatively about their own situation. Data was generated through a series of monthly workshops over a period of 30 months until a point of saturation was reached. The research facilitators and women engaged in a cyclic process of storytelling, reflection, learning and action planning. There was a high degree of flexibility as the process of data gathering involved continuous reflection and interpretation of the data in order to make decisions on how to proceed, based on what had already been discovered (Marshall and Rossman, 1995; Polit and Hungler 1997).

## Storytelling groups

Personal stories are seen as a powerful entry point into discussions and understandings of current conditions (Slim and Thompson, 1993). Stories allow people to reflect on and communicate about actions, describe how people and situations change as a result of actions, identify underlying problems, and recognise and seize opportunities. Stories allow those whose voices have been marginalised to speak on their own terms about their experiences. Storytelling is a culturally relevant method to use in African culture as everybody tells stories, thereby helping to overcome the problem of low literacy levels (Broodryk, 2002; Villa-Vicencio, 1995). Mattingly (1991:237) states:

Stories tell us who we are...[and] are perhaps the most fundamental form of communicating the sense of life and thus a sense of the person who lives that life... they provide us with a forward glance... helping us to anticipate meaningful shapes for situations before we even enter them, allowing us to envision endings from beginnings.

Stories illustrate the contexts of people's lives. Different events are chained together in a sequence, revealing the depth of problems faced by individuals and groups. Fourie *et al.*, (2004) found stories facilitated the exploration of the collective experiences of living in poverty or with a disability. In addition personal stories provide different perspectives on the lived experience of disability and poverty from that of the family member, CRW, or a health or development practitioner. According to Rubin and Rubin (1995) stories may communicate lessons, as people may describe themselves in ways that would be inappropriate to mention directly or openly in

normal conversation. Storytelling also reveal unintended outcomes that are usually missed by normal indicators, thereby uncovering the hidden costs (Slim and Thompson, 1993; Kreftig, 1992).

Storytelling would build the confidence of the person to speak out about their personal experiences (Slim and Thompson, 1993). Stories may give dynamic accounts of motives and intentions that form a focal point of concern. The value of this method for the study is linked to the skills developed through the process of telling a story. These skills could include confidence in dealing with disability issues, active listening skills in all interactions, active participation in decision-making, understanding group processes and group dynamics such as communication skills, conflict resolution, courage, trust-building and teambuilding. In a similar manner, stories could be a useful tool to describe experiences of building alliances between unfamiliar partners, i.e. disabled people, practitioners and researchers. The analysis of stories would facilitate reflection on practice, uncover deeply held beliefs, assumptions and images that guide actions, aspects of practice and experiences that are usually difficult to express. Thus storytelling could be a learning tool that helped the women share their experience of opportunities for development.

Matingly (1991) described certain limitations of the storytelling method. Public examination of the findings may determine the kind of stories that are told. Alternatively, the storyteller may have forgotten the details of their experience. Organisational and personal dynamics may influence the level of critical reflection that occurs. Power positions in the community, and perception of practitioners<sup>6</sup> as powerful, may mean that the women would be reluctant to give negative criticism. Many of the women would be accustomed to assuming roles of dependency and helplessness, with professionals taking responsibility (Shakespeare, 2000). In this study, the three partner organisations had very different organisational cultures, which could initially inhibit the women from sharing their stories. The research facilitators and CRWs would need to negotiate these differences and find ways of creating a space that was amenable to open sharing and building of trust.

### **Narrative Action-Reflection Workshops**

I conceived Narrative Action-Reflection (NAR) workshops from a realisation that we needed a method that combined the liberation education approaches, as described in Chapter Three (Hope and Timmel, 1995), and narrative inquiry (Marshall and Rossman, 1995). I define narrative action-reflection workshops as a combination of action-learning (Hope and Timmel, 1995) and storytelling (Slim and Thompson, 1993), so as to describe the meaning of human actions linked to larger social concerns (Clandinin and Connelly, 2000). The conceptualisation of the NAR workshop, as a data generation method, was based on my experience of the power of using the action learning approach in the training of CRWs (Lawana et al., 2003), the evaluation of CBR projects (Lorenzo and Saunders, 1999; Lorenzo and Sait, 2000), working with undergraduate and postgraduate students (Lorenzo, 2002), as well as groups of mothers of disabled children during workshops in rural areas (Lorenzo, 1998a; Lorenzo and Katzman, 1997). The workshops facilitated conscientisation and knowledge

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<sup>6</sup> Practitioners is used to denote any service provider who interacts with the women such as a community rehabilitation worker, a doctor, nurse, social worker, development worker, student or health therapist.

production, the two objectives of PAR, as described in Chapter Three. The workshops involved a group process that facilitates critical consciousness through active listening for generative themes from experience and problem-posing analysis to identify the root causes of one's oppression. A dialogue between facilitators and participants enable mutual learning from experiences so that individual or collective action taken can facilitate change, even in small ways. The cycle of action and reflection continued to happen within a workshop, as well as between and across workshops. Combining action learning with narrative inquiry enabled each woman to feel heard in a way that mobilised her to take action towards social change. NAR workshops were used in the second and third phase of the research to deepen our understanding of the factors discovered in the initial stories of the women.

Narrative inquiry was incorporated into the action learning process as a way to explore the needs and contexts of the women in more depth at different levels, namely, individual, family and community (Finlayson and Edwards, 1995). Narrative inquiry focuses on the individual's personal stories based on the assumption that people live 'storied lives'. Thus it seeks to collect data to describe these lives (Rubin and Rubin, 1995; Marshall and Rossman, 1995). The researcher constructs a narrative from the stories told. The narrative includes the signs, symbols and expression of feelings, using the words and idioms of the individual in a way that validates how the narrator constructs meaning (Marshall and Rossman, 1995). They comment further:

the inquiry should be a mutual and sincere collaboration, a caring relationship that is established over time for full participation in the storytelling, retelling, and reliving of personal experiences. It demands intense active listening and giving the narrator full voice (Marshall and Rossman, 1995:86).

Narrative inquiry has been critiqued for focusing on the individual and not the social context (Marshall and Rossman, 1995). Another shortcoming that they mention is selective recall. We were able to address these criticisms in the way we framed the study within the social model of disability. The stories were all gathered in workshops and not on an individual basis, so that the understanding about groups, communities and contexts was actually enriched. The nature of the group interactions and the use of creative activities as data triggers also addressed the concern of selective recall. In reality, as one woman shared her story, it resonated with experiences of others or triggered aspects of stories that may not have been spoken earlier. In addition, because we met frequently over an extensive period of time we were able to verify stories. The experiences were also verified through triangulation of research facilitators, which is discussed later. For many women, participation in the workshops helped them find their voice. Other disadvantages of the method relate to the fact that the participants in the workshops varied, although there was a core group of women who attended regularly. There were difficulties in organising transport and logistics. There were also time constraints.



### *Data triggers*

Data triggers describe the different creative techniques, activities and games that were used to create an atmosphere where women felt relaxed and comfortable to participate. The use of imagination and creative techniques is a non-threatening way of getting some resolution through engaging with our shadow side (Morgan, 1993; Hudson, 1995). Reason (1994:43) mentions that, when recorded, new experiences should be expressed in creative presentational form through graphics, colour, and so on. Creative

activities were used as “triggers”<sup>7</sup> or “codes” (Hope and Timmel, 1995) to get the women to reflect on actions and changes that have occurred between workshops (see Figure 6). These activities were used to facilitate sharing and exploration of their stories in small groups to explore specific generative themes, which were identified from analysis of the transcripts after each workshop, in more detail. (See appendix 5). Clay sculptures were also made as an alternative medium of expression, as this is a familiar activity in Xhosa culture. Workshops were characterised by much singing, sound, movement and drama, which created safe spaces conducive to participation, openness and exploration. In some cases, the women wrote the songs and poems.

Various techniques were employed to facilitate participation: icebreakers, brainstorming, use of pairs, buzz groups of three women or small groups of not more than eight women were used to encourage maximum

participation and dialogue by all the women present. The process ensured that the quieter members (often the younger members) got an equal opportunity to speak. There was a scribe and spokesperson from each group and a decision was made to group the women in terms of CRWs, newcomers and ‘oldies’ in specific workshops depending on the topic, in order to manage power dynamics. Small group discussions were not videotaped, but a scribe in each group



**Singing and dancing characterised the workshops**



<sup>7</sup> I have chosen to use the term ‘triggers’ in place of ‘codes’ as defined by Freire (Hope and Timmel, 1995) so as not to cause confusion with the term ‘codes’ used in the data analysis process.

kept brief notes to use in reporting back. With Marjorie and Peliwe as research facilitators in the workshops, there was a great deal of sensitivity between the participants and the research facilitators, as they were from the same culture and language group as the women. All the research facilitators had experience in counseling and group dynamics. As such, a conducive and safe environment was created in each workshop, where the women were supported and able to share their vulnerabilities (Meulenberg-Buskens, 1996; Hudson, 1995).

### ***Process of each workshop***

At the beginning of each workshop, women shared what actions had been taken and what had happened between workshops in the time spent waiting for everyone to arrive. After the welcome, an icebreaker was done to introduce the theme for the workshop. The women then participated in the trigger activity. Depending on the trigger activity, each woman told their story or one woman from each group reported back in Xhosa. The process had been discussed in depth between Majorie and myself beforehand, so Majorie knew where to probe or prompt for more information or description or seek clarity. Majorie has also had peer-counselling skills that were helpful in providing support and encouragement for women to open up. At the end of each workshop, women identified at least one action they would take between workshops. It was difficult to keep an accurate record of the review of actions at the beginning of the next workshop, as it was often led by one of the women, as they waited for everyone to arrive. Because of the disruptions of women joining, this first part of the workshop was not videotaped. But the process was important, as it was a means for the women to take ownership of the workshops.

### ***Workshop preparation and planning***

The research facilitators met monthly before each workshop to present the themes identified from the analysis, which informed the decisions on the content and process of the next workshop, through a process of consultative dialogues adapted from Smaling's (1998) concept of argumentative dialogues. They prepared a programme for each workshop, which was then negotiated with the women. Thus, the one adaptation we made in using PAR was that the women were not involved in the second level data analysis process that happened between workshops due to differing levels of literacy and logistical difficulties. It was also felt that it would encroach on the time they had for generating an income. We considered trying to secure funding to pay the participants for their time but did not opt for this approach as it may have biased the results. We recognised that as participant's confidence grew they would feel more confident to participate in the different research processes (Meulenberg-Buskens, 1996), although Price and Kuipers (2000) found that participants and facilitators may agree on different roles in the research.

### ***Data capturing methods***

All workshops were videotaped except three when there were technical hitches. They were videotaped rather than having simultaneous translation between Xhosa and English during the workshops, which would have interrupted the flow of women's stories and so run the risk of losing rich data. It would also have been too time consuming to translate for one person. All participants were informed about the rationale for using the video

camera. To minimise intrusion, we left the camera in a fixed position. Thus videoing was used more to ensure good quality audio-recording and not to record individual behaviour and non-verbal expressions consistently when women were in groups, as only one camera was used (Bottorff, 1994). Peliwe transcribed and translated all tapes simultaneously. She also reviewed videotapes for emotional content that occurred within the storytelling groups or NAR workshops.

### **Reflective Journaling**

As the primary researcher, I kept a personal diary and a research journal as a 'running diary' of my thoughts and responses to the women with whom we were working. The research facilitators also recorded their feelings and thoughts experienced before, during and/or between workshops or meetings (Rubin and Rubin, 1995) in order to generate textual data. I also reflected at the end of the day on the total process of what transpired in a workshop and in dialogue with my fellow research facilitators. I included how I felt about the interactions, where doubts arose, any issues related to power, confusion or niggles. This recording helped me recognise or become aware of gaps, what information may be missing or what we needed to explore in more depth as well as indicating where bias may come into the analysis:

None of us is sufficiently self-aware to always know exactly how we are reacting (Rubin and Rubin, 1995:120).

It was also in discussions with friends and colleagues that I was able to identify where I felt excited or what was frustrating me in the research process (Rubin and Rubin, 1995). Both the processes of reflective writing and dialogue helped me obtain some distance from the experiences and emotions in the relationships with the other research facilitators and women. Peer debriefing among the facilitators helped to enhance our skills. It was difficult to get my fellow research facilitators to keep a reflective journal. However, we addressed the need for research facilitators to be critically reflexive of own work by introducing monthly consultative dialogue meetings where we reflected on our own feelings, concerns and thoughts as well as giving feedback to each other. Marjorie and Peliwe did a mid-term evaluation of my role as 'primary' research facilitator.

Data was also generated from field notes (Matthews and Huberman, 1994; Polit and Hungler, 1997) related to what I observed or wanted to query from observations made during the narrative action-reflection workshops. Notes and reflections were recorded in a notebook and then transferred into my research journal, which was used as textual data. I made notes of any characteristics of individuals, recurring patterns of behaviour and relationships between participants; complex interactions or unusual events, changes in participants' appearance, behaviours and manner, routines; mental note of where /what to pursue further, particularly the meaning of any non-verbal communication that I observed; personal reactions to remarks and comments; levels of participation in activities, and any withdrawal or concealment, referred to as reactivity (Polit and Hungler, 1997). These field notes were shared and debated during the consultative dialogues, which occurred between the research facilitators as part of planning and peer debriefing between workshops.



These dialogues were purposive and expressive of deeper values and beliefs and provided opportunities to learn the different meanings that we attached to behaviours.

My observations were limited to non-verbal aspects because I do not speak Xhosa and was limited in listening to conversations. As all workshops were video recorded, there was opportunity to follow up and inquire with my fellow research facilitators at appropriate breaks in the workshop or afterwards in reviews. In this way, the participatory nature of the research process ensured credibility of results through shared ownership. Another weakness was my inconsistency in recording personal 'mental' notes made during the workshops or in dialogue with colleagues and committing them to paper. I did not systematically keep field notes on my observations outside of the workshops, as it felt too overwhelming to manage extensive data.

## DATA ANALYSIS

Data analysis sought to discover and weave together themes and concepts from the different sources of data, so as to create an accurate, detailed interpretation. Data refers to the transcripts of the stories and experiences during the groups and workshops that were captured on video for analysis and interpretation. Journaling and field notes were also considered as textual data for inductive analysis to develop themes. Comments on photographs were also recorded as data. In this way we were able to determine the meaning of women's experiences or develop explanations for their responses. A two-pronged approach to analysis was carried out. Firstly, at an organic level, analysis and interpretation were fused into the PAR process. As part of problem posing in the workshops, the women analysed the creative triggers using a six-step process (Hope and Timmel, 1995) (see appendix 4) to reflect on what they saw happening in the trigger and how it related to real life for them. This analysis was part of the dynamic interpretation of the emerging form of the study in order to direct actions by the women between workshops (Hope and Timmel, 1995; Taylor and Conradie, 1997). The process was captured on video and further analysed as part of the transcripts.

Secondly, at the structural level, the analysis had to answer the research questions. Peliwe and myself were responsible for the analysis process between workshops, so as to identify key themes to investigate further in subsequent workshops. We analysed the transcripts of each workshop using a combination of manual, open coding (Matthews and Huberman, 1994; Rubin and Rubin, 1995) for level 1 analysis of workshop transcripts to identify the barriers and strategies for development (see Chapter Five). The analysis happened simultaneously from early on in the study, so as to inform further data generation. A second level of analysis occurred as part of data interpretation, where our findings were triangulated with literature. Reflective stance approach (Meulenberg-Buskens, 1999) was used for a third level analysis of data longitudinally to determine the nature of the actions and changes that occurred during the period of the study (see Chapter Six). The inductive process of analysis allowed the research facilitators to report on the context, as well as linking the phenomenon under study to the context in which statements were made (what had happened before or after), who made them, how responses of informants varied in relation to contextual variables (Thorne, 1994).

## Manual, open-coding analysis

Analysis of transcripts from monthly workshops provided 'slices in time'. The two research facilitators read and re-read the transcript of each workshop "paragraph by paragraph, and word by word, marking off each time a particular idea or concept is mentioned or explained, and indicating with a code the subject of each paragraph" (Rubin and Rubin, 1995:227). Meaningful units were identified and labeled as codes, which helped organise what the women had contributed. We also looked for phrases that were repeated frequently and seemed to be expressing an important idea. We looked for any opposite or contradictory comments related to the same idea or concept, e.g. the purpose of disability grants. We then met together to compare our findings, which were discussed at the monthly consultative dialogues to inform the planning for the next workshop.

Codes that described the same ideas or concepts were grouped into categories that were labeled to reflect the underlying meaning. In some instances, a direct quote was used to label a category (Matthews and Huberman, 1994). Categories helped us compare what different women said and how issues were understood. The process illuminated new insights and understandings. The categories were then collapsed to establish themes and arguments that would support, modify or contradict existing theory or policy. Themes arose from the categories that were identified inductively from the data. They identified concepts that reflected major points, arguments or tensions with particular reference to the research questions. Themes also provided descriptions of how the women perceived the factors that influenced their development. In some cases, the themes suggested explanations for why and how things happen (Rubin and Rubin, 1995). Naming the themes involved a choice and combination of the women's own words in some instances, or reaching agreement between the research facilitators on the best phrase for capturing the meaning. We overcame one of the disadvantages related to difficulties in data analysis linked to not understanding the contextual surroundings, as we had worked with the women in their context over an extensive period of time and formed very meaningful and open relationships. Marjorie lived in the township adjacent to one of Nyanga's districts. A second approach to analysis was used to gain a longitudinal perspective.

## Reflective stance approach

The reflective stance approach (Meulenberg-Buskens, 1999) was used to analyse the transcripts from across the NAR workshops, so as to construct stories of action. The analysis, therefore, provided a longitudinal perspective across the study period. The approach consists of six steps, which were followed by the two research facilitators individually. We noted the shifts and changes that the women spoke about in the workshops. Changes in interactions with perceived leadership were also noted. We then met together to compare our findings on the changes that had occurred.

The first step involved reading and re-reading the text. The second step identifies the main issues that 'jumped out' for us. Step three considers the formulation of a theme from or on the basis of the issue. Step four required that we scrutinise our relationship with the theme. We looked at whether this theme occurred in

our own life or work. Was it part of our pet theory? Writing about it not only contributed to our understanding of the text, but of other texts to come. This step also allowed us to reformulate the theme if needed. In step five, we selected a theoretical concept (or lens) to give new meaning and understanding to the theme. Step six involved a continuation of the five steps until the text is exhausted. In each step, the researchers observe and watch their reaction, thoughts and emotions, while 'doing justice' to the text. Our reactions, thoughts, and emotions were written down, one by one, in the margins of the transcript. Themes were named to illustrate the nature of the action taken or change that occurred. A narrative was constructed, and where relevant, direct quotes of women were used to provide thick description so that the reader is able to judge the relevance to another context (Kreftig, 1991).

## Data interpretation

Next, we entered into dialogue on the interpretation of the data. We took our guide from Rubin and Rubin (1995:227) who comment that:

The analysis is complete when you feel you can share with others what your interpretation means for policymaking, for theory, and for understanding the social and political world.

The interpretation of data seeks to capture insightful conceptualisation that goes beyond common knowledge on disability and development (Polit and Hungler, 1997). The process also contributes to the development of recommendations that were relevant to current policy and development practice or to curriculum development for professional education. Polit and Hungler (1997) have identified the various dimensions of data interpretation that we kept in mind and considered. Firstly, the accuracy of results was sought by establishing credibility amongst the participants. Secondly, the research facilitators established rapport through sustained immersion and also through consultative dialogues amongst themselves. Thirdly, using thick descriptions<sup>8</sup> from the women's stories enhanced the meaning of the data. The importance and relevance of the study was supported through a review of relevant theoretical frameworks and literature linked to themes as the study progressed.

Various theoretical frameworks informed the data interpretation process, as a means of triangulation following an inductive thematic analysis of the transcribed data, as described in Chapter Two. Firstly, Human Scale Development (Max-Neef, 1991) provided a deeper appreciation of the complexity of poverty and disability experiences. Secondly, the UN Standard Rules On The Equalisation Of Opportunities For Disabled People (UN, 1994) provided a tool to monitor how the women were able to access opportunities for development. The social model of disability and literature on CBR and occupational therapy were also applied. We were also able to monitor how, through their actions, women progressively attained a change in their status and participation in opportunities in their communities and organisations. Thus PAR provided an

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<sup>8</sup> Thick description refers to giving detailed, rich description of the women's experiences, sometimes using their own words (Kreftig, 1991).



opportunity to explore the operationalisation of the Rules in addressing the experiences of human poverties and disability discrimination in the development of the women in this study.

## VERIFICATION OF AUTHENTICITY OF DATA

The next section describes steps taken to ensure rigour and authenticity of the research process. The concept of 'trustworthiness' reflects the 'truth' value of the research by looking at the extent to which the findings are 'true' and accurate and reflect the reality and ideas of the participants (Holloway, 1997). According to Lincoln and Guba (1985 in Holloway, 1997) and Polit and Hungler (1997), there are four criteria that increase the trustworthiness of qualitative research.

### Credibility

Firstly, credibility exists when the participants recognise the truth of the findings in their own social context. The research findings were compatible with the perceptions of the women. Credibility was achieved by the research facilitators immersing themselves in the setting and by prolonged engagement with the women. I was vigilant to ensure that the women were the 'authors' of their stories of development and that the meaning of their experiences was accurately documented.

Focus groups were used for member checking with the participants, as Marshall and Rossman (1995:84) point out that:

The method assumes that an individual's attitudes and beliefs do not form in a vacuum: people often need to listen to others' opinions and understandings in order to form their own.

An advantage of PAR is that it allowed flexibility if the research facilitators wanted to explore new issues that arose in the feedback and subsequent discussion, as ideas are sparked off as people speak, suggesting dimensions and nuances of the issue that as individuals they may not have thought of, giving rise to a totally new understanding of the issue (Rubin and Rubin, 1995).

Member-checking was done regularly during the study at three-month intervals, as it allowed an opportunity for the women to confirm the 'truth' of the findings by verifying the analysis and interpretation done by the researchers (September, February and May.). There were usually between 20–25 women present, which is a larger number than normal for focus groups. We felt that women would be more comfortable in challenging our interpretations as a group, as it is culturally familiar structure for dialogues. For some of the workshops, I had taken photographs, which were later used in member-checking using powerpoint presentations, as we asked the women to reminisce about the meaning of the photos. Different formats were used such as giving feedback through piloting poster and conference paper presentations with the women (Lorenzo 1999; Lorenzo *et al.*, 2000; Lorenzo 2001a; Lorenzo 2001b; Lorenzo 2003). Power-point presentations and seminar presentations were also

done in preparation for the UWC Summer Programme for the School of Public Health and DPSA women's groups in Northern Province (now Limpopo) and Mpumalanga. In this way, findings and interpretations were verified. Re-examining the women's stories in preparation for seminars or conferences also seemed to confirm or disconfirm the tentative themes that had been named. Literature was used to refute or support the interpretation of the findings. Annual evaluation and planning workshops with the women ensured that the women participated in the decision-making process of the programme for the year.

Various peer-debriefing opportunities included the monthly consultative dialogues with the research facilitators, an opportunity to present to the postgraduate research group of the division of occupational therapy, as well as communication with SG, a fellow community occupational therapist, and disability rights activist. She was Xhosa-speaking and lived in the township next to Khayelitsha.

### **Transferability**

The second aspect of verification is transferability. Trustworthiness is enhanced when the findings in one context can be transferred to similar situations or participants (Holloway, 1997). 'Thick description' is a narrative that is developed about the context and women's experience of disability to provide an accurate and detailed synopsis of the data in context, which was presented to peers and readers at different seminars or conferences, so that they had a clear picture of what happened (Kreftig, 1991). It allows the reader to determine the relevance of the findings to other contexts.

The various seminars provided an opportunity to determine the transferability of results to other contexts and programmes for development of disabled women, especially those living in rural and peri-urban areas in other provinces. The process enabled dialogue between the women in Khayelitsha and women in similar contexts in different provinces. Therefore, the research provided sufficient description of the context in which the data was collected and analysis of key parameters of the context of the study to allow people in other contexts to benefit.

### **Dependability**

Thirdly, dependability reflects the details of the research process. Guba and Lincoln (in Holloway, 1997) suggest that the consistency and accuracy of a study may be demonstrated through keeping an audit trail, which is a detailed description of the path of the research so that the decision-making processes can be followed by readers. Data was collected until a point of saturation was reached. The audit trail of this study was drawn from the minutes of meetings, the audio and video recordings and journaling. The phases of the research are described in this chapter, and the data triggers and details of the timeline are provided in the appendix. The potential pitfalls of the different methods have been highlighted. A detailed reflection of the NAR workshops as a relevant method for data generation is discussed in Chapter Eight.



## **Confirmability**

Fourthly, confirmability ensures that the findings are an accurate reflection of the women's experiences, and not the outcome of the biases and subjectivity of the researcher (Holloway, 1997). The decision-making process has been made visible in the detailed description of the phases and analysis process, as well as the provision of the timeline (see appendix 6). The representation of data has been recorded using an audit trail in such a way that that data may be traced back to the origins.

## **BRACKETING ASSUMPTIONS**

I attempted to minimise the impact of my assumptions by declaring the biases I was conscious of, and by being receptive to feedback through an approach of open-mindedness and open-heartedness (Smaling, 1998). I requested feedback from the research facilitators, both formally and informally. We established safe spaces for dialogue using creativity as described earlier. I was willing to help women with problem solving where needed. The process of dialogue and discussion in the early phases of drawing up the proposal and the continuous reflection helped to reveal the different assumptions that were present.

I was aware that we were entering the social world of the women. Their social worlds were meaningful places, places full of active subjects, not passive objects. I was confident that the women would be able to share their experiences and that they would be active and participate in the research process if they found it relevant to their development. I was also confident that the research process would generate knowledge and insights that would benefit the women's development positively. I believed in the potential of the women as agents of change who each had potential to create a better life, if given the resources. However, I was aware that many women seemed more concerned with daily survival rather than with political emancipation. Such concern could be due to the fact there was insufficient awareness of the political nature of the problems they experienced. Thus, PAR with the women could have transformational potential, especially as the one research facilitator, CRW co-ordinator and the CRWs had personal disability experience, which helped shaped the development of the aims, methods and the relevance of the research.

## **ETHICAL CONSIDERATIONS**

The study took place in a social context that demanded professional ethics, control by the participants and accountability to the public. The ethical decisions of this study were informed by critical theory and the principles of EDR (see Chapter Three). Both these frameworks sought to address the imbalance of power within the research process and the privileged position of the researcher to set the agenda and control the outcomes (Hagey, 1997; Kitchin, 2001). Literature on disability research questions and challenges the degree of independence and accountability of the researchers (Barnes and Mercer, 1997). The methodology, therefore, had to enable an understanding of the phenomenon of impairment and disability and the

experience of disabled women in a way that would ensure accountability to them. Both Hagey (1997) and Kitchin (2001) claim that inclusive approaches facilitate interaction. These approaches enforce a rigorous approach and increase validity as it gives the participants a stake in the quality of the research. The major principles of social justice guided the PAR study, namely, equity, restitution and procedural justice (Hagey, 1997).

At an organisational level, several steps were taken to ensure that ethical standards of research were guaranteed.

- Verbal permission for the study was sought and obtained from the SACLA Rehabilitation Management team. I attended the management meetings on a monthly basis to give and receive feedback. I also assisted in strategic planning during the period of the study. Regular written reports were provided for their annual reports.
- A research proposal was submitted to the Faculty of Health Science's research committee and approval obtained for the study.
- A commitment to participation was negotiated with the women in the first workshop of each year. The research assistant completed a register of participants for every workshop by recording the names and addresses of each woman present. These forms were kept on file by DPSA as a record. Informed consent was given verbally due to differences in literacy levels. In this way, we were able to track those women who participated frequently. The informed consent (see appendix 7) process provided the opportunity for participants to withdraw at any stage if they so wished, as well as accountability through participation. Verbal permission to video-record and take photographs was sought from the participants at the start of each workshop. They were also assured that they could request for the camera to be turned off at any time. Videoing seemed to actually build confidence in the women who wished to be seen on TV. Participants gave permission for the photographs to be used for conference presentations and published in the book and thesis.
- To maintain confidentiality, we decided not to identify women by their own name or specific area in reporting the findings (Morse, 1998; Thomas, 1998), even though women said we could use their names. We were concerned that there may be unforeseen repercussions, and rather erred on being cautious in changing the names of the women. Due to the mixture of individual and the collective reporting from small group discussions in the workshops, the use of quotes to substantiate the analysis and provide in-depth descriptions are reported as 'some' or 'many' to indicate where a woman reported for the group she was in during the workshop. 'One' usually indicates where the woman spoke for herself.

- In discussing the interpretation of the findings, the facilitators decided to use 'we' in line with the participatory nature of the methodology, as decisions were made as a team in the monthly consultative dialogues. Thus, in writing up findings and discussions of the study, it is difficult to separate my thoughts and insights as they were equally influenced by the dialogue and debates that occurred.

Furthermore, we decided that our professional conduct during the research process would be guided by Oliver's (1997) three foundational benchmarks for emancipatory disability research: gain, reciprocity and empowerment, as well as the principles of EDR for transforming researchers as 'parasite people' into partners to achieve the goals of disability research (Stone and Priestley, 1996; Kitchin, 2001) (see Chapter Three). Two of their six principles provided specific guidance in the ethical considerations for the study, as described here. They raised the question 'What's in it for them?' In looking at issues of irrelevance and benefit, the principle demands that the researcher does not sit comfortably within the academy, but confronts the accusations of irrelevance from disabled people and their organisations. Therefore, the researchers need to look at how the research will improve the lives of the research participants, who should determine the nature of engagement. We were confident that the action-learning process would enable the women and facilitators to identify barriers that needed to be removed and then plan actions and strategies for their removal. As mentioned earlier, Marjorie's skills in peer counselling would provide a resource for emotional containment for the women where necessary. The women would become 'sources' of knowledge and their meaning would become 'material' in the research process. The challenge was that I could not merely further my academic career and publications, but would need to ensure that there was meaningful change for the women as well. The relevance of the research to the lives of the women would be judged on these changes, which meant the extent to which the research process contributed to the identification of ways to address disabling social and physical barriers. The facilitators' political standpoint on disability was tied to political action in challenging oppression experienced by the women (including internalised self oppression) and facilitating their self-empowerment.

The social and material relations mentioned in Chapter Three have bearing here. The focus on activism to effect practical change is arguably the most fundamental principle of the emancipatory paradigm. If research is to become useful and relevant (Oliver, 1992; Stone and Priestley, 1996), the social relations should demonstrate commitment in actions as well as words. Thus a reversal of social relations of research production is required whereby the researcher engages in the emancipatory struggles of disabled people, by disabled people through laying his or her skills at the disposal of disabled people, "for them to use in whatever way they choose" (Barnes 1992:122). As one of the research facilitators, I had met and worked with some of the women two years prior to the start of the study. Thus, combined with my rural experience in disability and development, I had learnt how to put my knowledge and skills at the disposal of the disabled people and their families for them to use in whatever way they chose. We were also confident that we would be able to achieve this sharing of skills further in this study, as there were three research facilitators, as explained earlier, so our skills complimented each other. Two of the facilitators would be able to further

demystify the research process for the women in their own language, as well as raise critical issues or concerns in our monthly dialogue and planning meetings.

The social relations of research production also extend to who controls the finances. The findings should be widely disseminated to a variety of different audiences. The question should be asked about “What should happen next?” to take things further. Some critics of PAR may see the study with the women as more participatory than emancipatory as the women themselves did not control the research funds as the university administrators and funders would not allow this for accounting purposes. However, the women were involved in decision-making related to how the funds should be used and who should be involved and how.

## **REFLECTIVE SUMMARY**

This chapter has presented the different aspects of the research design. A description of the research facilitators and the participants was provided. The data production methods were outlined in detail, and the ethical considerations highlighted.

Chapter Five will present the findings and dialogue on the experience of the barriers and strategies of the disabled women.

University of Cape Town

## Chapter 5

# Discovering the Barriers and Strategies for Equalizing Opportunities: Findings and Discussion

### Introduction

#### PART 1 Personal experiences of the women: findings

##### **Cycle 1: *Our lives have totally changed:* at an individual level**

Loss of power: *Nothing seems to help*

Dispelling myths of laziness: *We don't just sit*

##### **Cycle 2: *All the loads are ours:* at a family level**

Disability as a burden: *Our souls don't rest*

Disability as a gain: *Doing a lot with a little*

##### **Cycle 3: *There are so many things happening in our lives:* at a community level**

Imposed boundaries: *So we gave up*

Extending boundaries: *Bettering our lives*

#### PART 2 The complexity of disability: discussion

### Introduction

#### Deprivations and potentialities

**Self-identity: loss and agency**

**Family life: pain and pride**

**Sustaining a livelihood: missed opportunities and providers**

**Health and social services: ignorance and CRWs as a buffer**

**Accessing resources: marginalized and potential to be free**

#### PART 3 Planning for further action: suggestions



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# Discovering the Barriers and Strategies for Equalizing Opportunities: Findings and Discussion

### INTRODUCTION

This chapter is comprised of three parts that address the first objective of the study (see Figure 7 below): Part One focuses on findings from the personal experiences of the women (steps of action-learning cycle – ‘doing’ and ‘seeing’). Part Two presents the discussion on the complexity of disability. The interpretation by the research facilitators triangulates and integrates the findings from all three cycles with relevant literature (a step of the action-learning cycle – ‘thinking’). The integration of the findings from the three cycles is presented in Figure 8 using Human Scale Development (Max-Neef, 1991) and the UN 22 Standard Rules (UN, 1994) as the organising framework. The chapter culminates in the ‘planning’ step by providing critical points for exploration in ‘Ideas for further action’, which will take us into the next phase of the study. Thus, the documentation process is aligned with the iterative, cyclical and developmental nature of PAR methodology.





Figure 7.  
Personal experiences of the women

PERSONAL EXPERIENCES OF THE WOMEN: FINDINGS

The findings are described in three cycles linked to barriers to and strategies for development at individual, family and personal levels respectively. These divisions are ‘artificial’ and used to present the analysis of data. I highlight the sub-themes and categories in bold type and present the substantiating quotes from the women’s stories in italics.

Cycle 1    *Our lives have totally changed: at an individual level*

Cycle 1 of the PAR study explored the barriers that women experienced at an individual level as a consequence of their impairment and the strategies they used to overcome these barriers. The central theme from this data set was “*Our lives have totally changed*”. The women described living with their impairment as distinctly different to the life they lived before the onset of impairment. The change was ascribed to a range of losses as a result of the acquired disabled status.

There were two dominant sub-themes for this set of changes (See Table 4 below). On the one hand, “**loss of power**” revealed the barriers related to the losses experienced by the women. On the other hand, change was ascribed to the strategies they had to adopt to dispel the myths commonly associated with disability. The dominant sub-theme for this set of changes was “**dispelling the myths of laziness**”. Thus the complexity of disablement emerged through the sub-themes. The personal impact of impairment resulted in a number of losses on the one hand and the discovery of a range of innate capacities on the other. A number of descriptive categories of data substantiate the women’s personal experience of this paradox. Although they experience the loss of dreams, worker role, hope and health, they find within themselves an emerging sense of agency and a desire to work in spite of the numerous barriers confronting them.

Table 4: Themes related to personal experiences at an individual level

THEME	SUB-THEME	CATEGORIES
<i>Our lives have totally changed.</i>	<b>Loss of power:</b> <i>Nothing seems to help.</i>	<ul style="list-style-type: none"><li>• Loss of dreams</li><li>• Loss of worker role</li><li>• Loss of hope and health</li></ul>
	<b>Dispelling the myths of ‘laziness’:</b> <i>We don’t just sit.</i>	<ul style="list-style-type: none"><li>• A sense of agency</li><li>• A desire to work</li></ul>

Besides the few women who had congenital deformities, most of the women had known a different way of life and being in the world. They were, therefore, able to reflect on the impact of impairment on their development. They reported, in essence, that their lives had totally changed due to a diverse range of losses.

Substantiation of the main theme *“Our lives have totally changed”* now follows with reference to each of the two sub-themes and supporting categories (see Table 4 above). Excerpts from women’s stories have been selected for their richness to illustrate the category or theme. The selection of quotes provides a ‘thick description’ of commonalities and differences in contexts and experiences.

### ***Loss Of Power***

*In my picture I have drawn myself as a fat beautiful person because that’s what my parents wished me to be. But these wishes were not granted because I got disabled when I was at school. A horse kicked me while I was sitting in front of a house, and I broke a leg. (Nozuko Nov 1998)*

The onset of impairment shattered the cultural ideal of daughters becoming fat and physically beautiful and parental hopes of having eligible daughters for marriage in the future: an attribute highly valued in securing a range of female roles and, therefore, a sense of identity. Some women experienced the **loss of dreams** related to these culturally valued feminine attributes, as well as the loss of dreams ascribed to an inability to fulfil their roles as wives, girlfriends, daughters, mothers and sisters since the impairment. Such losses often exacerbated a feeling of low self-esteem and self-worth. This, in turn, impacted adversely on the development of a strong sense of identity.

Angela’s story offers a rich illustration of the loss of power associated with these dreams. She was middle-aged, and had sustained fractures of her left leg, upper arm and hand in a motor vehicle accident in 1997. These injuries left her unable to walk without crutches. Furthermore she had difficulty carrying out household activities such as cooking and cleaning. She was the eldest daughter and had a child herself. She was not getting a disability grant. After sustaining the impairment, Angela no longer felt like “a star” that shines and brings light and hope because she felt unable to fulfil the culturally prescribed roles of women:

*I have drawn a picture of a star because that’s what I wanted to be. And then I was disabled. A car hit me and I broke my leg and arm ... so being the eldest [at home] I was supposed to help my mother because my father was dead. I have got one daughter who doesn’t help me... I don’t get any disability grant ...I don’t want to feel helpless as I’m feeling now. (Angela, Nov 1998)*

Her low self-esteem and self-worth appeared to be rooted in beliefs about not meeting social expectations related to what is normally expected of daughters in looking after the surviving parent when one of them dies. She described feelings of helplessness and guilt because she no longer had an identity in her helping roles. An added frustration was her daughter who, in turn, was not fulfilling her culturally prescribed role of supporting her mother.

The loss of power as a consequence of their impairments extended to the **loss of the worker role**. This influenced their ability to meet family needs as seen in the following quotes from the stories of different women's experiences:

*The doctor referred me to N Workshop for the disabled and I was involved in sewing. After some time the workshop was closed. therefore, I lost the job. I am dependent on the disability grant. It is difficult to send my child to school. My wish is to get another place where I can start doing sewing again. If I had a sewing machine I would sew at home. That is why I would like to go to another place like N Workshop. (Vuziwe, Nov 1998)*

*I left the Transkei to come to Cape Town because my children were not writing or supporting me. I don't have a husband... I am looking after two children of my daughters, and recently my son got epilepsy. I have been working in a nearby crèche but recently I can't manage anymore because of [my son's] attacks [fits], and my legs are now swelling up...the only person that helps me with food is my neighbour who also owns a crèche. (Fikiswa, Nov 1998)*

*I have been working [as a domestic worker] but I couldn't continue because of the attacks [fits]. I wish to be very independent like selling things on my own. My life has totally changed, especially now that I don't get a disability grant. I have many problems and it's hard for me to live a normal life. (Nophindile, Nov 1998)*

These quotes from the stories of three women illustrated different aspects of the loss of worker roles. The few sheltered workshops in Khayelitsha that were provided by NGOs for disabled people such as Cape Mental Health or Workshops Unlimited<sup>9</sup> had been shut down due to lack of funding. Such closures resulted in a huge loss for the women in terms of potential employment opportunities. This loss seemed to exacerbate their feelings of isolation and hopelessness. Some women identified a place to work as an essential resource for development and independence and reported an acute loss of potential productivity when access to these facilities was denied or stopped.

Fikizwa was the sole breadwinner in the family. Her ability to work was further limited by her son's impairment. She was left feeling dependent on the neighbour's willingness to support her, as her neighbour had a source of income. This dependency often exacerbated an existing sense of loss associated with fragmenting family structures as seen in Fikizwa's story above. Phindiswa was also struggling to live a normal life after the impairment. Her sense of powerlessness was exacerbated when her grant was stopped.

The facilitators went on to explore further the aspect of finding work as a means to develop self-reliance:

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<sup>9</sup> These NGOs had to fundraise independently to sustain the workshops.

TL: *What's the reason why you can't do [jobs]?*

Woman: *I don't know why we are not getting jobs. They say they go and look for work. I've never done that, but I have my own business. I haven't looked for work.*

TL: *Why are you not looking for a job?*

Woman: *I was thinking if I could go and look for a job, I couldn't go to those jobs where I will be required to lift heavy things. I thought I would grow and develop, but it didn't work like that. (May 2000)*

The stories revealed that the women felt **vulnerable to ill health**, accompanied by a **loss of hope** from a sense of helplessness, as they had to deal with a myriad of social problems. The inability to do everyday activities was identified as a barrier to development as it exacerbated their feelings of powerlessness imposed by the impairment:

*I have drawn a picture of a house with a candle inside. The candle reminds me of the days before I got disabled. My disability is epilepsy. This disability has made me to be unable to do things that I would like to do as a normal person. When I start anything I start having the fits. It makes me dependable on other people like children and my neighbours. Although I take my treatment, nothing seems to help. (Phindiswa Nov 1998)*

Fikizwa shared with the group how her impairment had rendered her unable to do much even though she actively sought health care:

*My disability is that I have pins and needles in my legs and in my arms that makes me unable to do anything. I am now at home not working and not getting any disability grant. I would like to do something to help myself but my arms and hands become stiff...I have been attending [a district hospital providing primary level care] but I don't get well. I'm going to request my doctor to transfer me to some specialist because, as it is, I can't do anything with the problems I have in my legs and my arms. (Fikizwa Nov 1998)*

One woman felt that her fragility limited her ability to be actively involved in everyday activities. Medication did not seem to help or bring any reprieve to her enduring feelings of dependence due to the impairment:

*In my nature I'm a disabled person because of my poor health. I have fits. I see myself as a glass because you can't just put a glass [down anywhere]. I always get sick so I have to take care of myself and not just go anywhere because I might get sick. So that's why I identify myself with a glass because it just breaks... I take [medication] on a daily basis. (Zoleka, Nov 1998)*

In summary, the loss of dreams, worker role, hope and being vulnerable to ill health captured the essence of the personal barriers facing the women. These losses culminated in feeling a profound loss of power to direct their affairs, an experience of feeling as if “*nothing seems to help*”. The aspect of powerlessness showed the complexity of the interactions between poverty and disability for the individual and the family. Whereas the loss of power was something one may expect of women with impairments, the other side of the picture showed how resourceful the women could be despite myths related to inability and dependency, as a consequence of impairment. These stories are explored in the next theme.

### ***Dispelling myths of laziness***

*The only thing that I do is to buy and sell sweets... My wish is to have things that other people are having. I don't want to feel helpless as I am feeling now. I would like to start something with other disabled people, which can make us independent.* (Angela, Nov 1998)

Although Angela's story earlier (see pg. 78) described the barriers she experienced related to her loss of identity associated with a sense of dependency, she also recognised the need for skills development and the strength that she could potentially gain from collective action. Ironically, due to high levels of general unemployment and poverty, many women who received disability grants were the sole breadwinners in their households; this is in contrast to non-disabled women who were unable to secure a steady job. A number of disabled women used their disability grants as seed money to increase their income. In doing so, they dispelled the myth of 'laziness' that was associated with stereotypes of helplessness, inability and dependency as a result of an impairment. Such actions reflected **a sense of agency and a desire to work** amongst the women who aspired to become successful in their small business initiatives. The sub-theme “dispelling the myths of laziness” may be summarised in the women's words: *We don't just sit and fold our arms.*

There was a strong feeling among the women that they were hungry to regain their **sense of agency**. They shared dreams of developing an alternative identity and of regaining autonomy. There seemed to be a strong inner motivation to be independent so as to overcome a sense of dependency and helplessness.

As in Angela's case, other women considered various forms of informal trading as a means to improve their income to meet family needs. In addition, by being agentic as opposed to victimic<sup>10</sup> and passive, they had gained access to training opportunities through the programmes of NGOs and disabled people's organisations (DPOs). In this way their impairment served to improve the family's situation. Thus they dispelled the myth of laziness:

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<sup>10</sup> The terms 'agentic' and 'victimic' were used by Polkinghorne (1991).

*The solution to the burden [of impairment] is to try and do handwork and sell or to buy with that small money and make 'vetkoek'<sup>11</sup> and sell them. You can sell fruit or any other things that are easy to sell so that you can get money and do things e.g. you have children that you want to take to school. So by selling you get money and develop and not just sit and fold your arms. Your load becomes lighter. (Collette, April 2000)*

The women challenged the myth of laziness by their engagement in everyday activities and work. One woman represented herself as a strong donkey able to manage her responsibilities:

*I'm also disabled just like others. I have two boys who live with me as a disabled person. I'm not lazy to do things by myself. I'm a businessperson and I wake up early to get material for sewing. Even this skirt I'm wearing, I made it with a machine. I do things for myself though I'm disabled... I saw myself as a donkey ... everything is my responsibility and I can manage. (Mary, March 2000)*

The women's sense of agency focused on matters related to ordinary lives and their concern for family well-being by overcoming dependency. They saw no reason why they should not have what others have. Another child had beaten Vuziwe when she was fourteen years old. She was left with a hemiplegia and spoke proudly of her experience of having given birth to a child whom she had raised successfully, despite her impairment. Her story continued:

*I was taken to [a tertiary hospital] and I went there for a very long time. When I left the hospital the doctor gave me a letter for a grant. I got the disability grant [DG] ... I fell pregnant. My child is seven years old now. (Vuziwe, Nov 1998)*

The stories indicated that although the impairment had changed their lives dramatically in terms of a range of losses, they had not lost their **desire to work**. Work was seen as a means to overcome the feeling of despondency and the numerous losses they had experienced. They took action to improve their situations, which often involved a journey of more than 1 000 kilometres from rural areas in the Eastern Cape to seek work in Cape Town. Kholeka's story is one that dispelled the myths of inability and dependency as she sought the means of self-employment in the informal sector:

*In 1993, a bus hit me and both my legs were broken. I was sent to hospital and on my discharge I was much better. I was given a letter to apply for a disability grant that was successful. I started brewing beer to increase my profit. This was also successful. (Kholeka, Nov 1998)*

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<sup>11</sup> 'Vetkoek' is similar to a doughnut, round in shape and deep-fried.



Within the group, there was no shortage of ideas or aspirations to succeed and be economically empowered . Other disabled people who had succeeded in overcoming the barriers to family life and work were a source of motivation and role-modelling to the women. Women continued to problem-solve:

*I have this small business; I have this family. If government could give us our own place [to work], then we can do our things to develop ourselves.* (Noxolo, March 2000)

In summary, the stories showed that the women were able to identify and respond to their own needs for development. Their sense of agency and desire to work helped the women regain their ability to dream and fulfil their roles again, their hope, their health and well-being. They were not merely passively dependent on disability grants, but they used their grants as seed money to empower themselves. Their desire to work had changed their lives for the better. Many women were self-employed in the informal sector, yet still sought employment in the open labour market. The stories provided evidence that many women had acquired skills for income generation, but wanted to go beyond work as a means of survival. They also benefited from being positive role-models for each other as they dispelled the myth of laziness.

**Cycle 2    *All the loads are ours: at a family level***

The first cycle focused on personal experiences at an individual level. Cycle 2 continues to uncover barriers and strategies of women by describing the experiences of their families and households. The women narrated the fabric of their daily lives within the home in the words: “*All the loads are ours*”. This central theme is substantiated by two sub-themes (see Table 5). The women experienced **disability as a burden** within the household to the point that “*Our souls don’t rest*”. In contrast, **disability as a gain** shows how the women managed the responsibility of “*Doing a lot with a little*”. The strategy of the load as an asset was captured in this second sub-theme showing the agency of the women in the face of adversity in more depth following Cycle 1.

**Table 5: Themes related to personal experiences at a family level**

THEME	SUB-THEMES	CATEGORIES
<i>All the loads are ours.</i>	<b>Disability as a burden:</b> <i>Our souls don’t rest</i>	<ul style="list-style-type: none"> <li>• Fragile networks</li> <li>• Emotional exploitation</li> <li>• Financial exploitation</li> <li>• Loss of cultural traditions</li> <li>• Strained family relations</li> </ul>
	<b>Disability as a gain:</b> <i>Doing a lot with a little.</i>	<ul style="list-style-type: none"> <li>• Optimising disability grants</li> <li>• Voicing needs</li> <li>• Fostering reciprocity</li> </ul>

The women experienced a breakdown of family structure with the frequent migrations between their homes in the rural areas of the Eastern Cape and the urban sprawl of Khayelitsha and Brown's Farm on the outskirts of Cape Town to access health services and job opportunities. Substantiation of the main theme "*All the loads are ours*" now follows with reference to each of the two sub-themes and supporting categories.

### ***Disability as a burden***

The disruption to family systems as a result of rural-urban migrations resulted in **fragile networks** for many women. Their stories painted the same bleak picture of the various factors that contributed to disability as a burden. These included the death of parents, onset of illness or impairment and subsequent losses, which left many women feeling more vulnerable.

*I grew up with a hunchback. We lived in the Transkei<sup>12</sup>. I came to Cape Town with my mother because she was sick. My mother died leaving me alone with her youngest child (Nonsidiso, Nov 1998).*

*I was born in Transkei and came to Cape Town with my mother. After a time, as we were working on farms, my mother passed away. (Kholeka, Nov 1998).*

*I have drawn a house here with a candle. The candle symbolises me as a spark at home before I got disabled. I used to light this candle when I pray to God for strength. Then I got an eye problem ... at that time I was in the Transkei. But when I grew older I came to Cape Town as the eye problem became worse. (Philiswa Nov 1998)*

Domestic violence and abuse created an additional load for the women, who not only had to negotiate the functional implications of their impairment, but also the emotional and physical consequences of enduring conflict. Other factors that contributed to the fragile networks were unemployment and substance abuse in the family, which exacerbated the impairment:

*I stay with my children and I don't have a husband. There are so many things happening in my life. One child was stabbed and the other one was burnt with hot water by his girlfriend. My soul doesn't rest. I wish I could stay alone and not meet with other people because I'm not happy. (Ncebakazi, March, 2000)*

*I have also got another problem: the father of my children is a drunk and drug addict. He beats me now and every time I reported him to the police and the street committees but he doesn't stop. (Fikizwa, March 2000)*

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<sup>12</sup> A rural area in the Eastern Cape, approximately 1 000 kms from Cape Town.

Philiswa's story (mentioned earlier in Cycle 1 on losses) was particularly distressing as it accentuated the consequences of physical abuse and social disintegration experienced by the women. She had had a successful eye operation after coming to Cape Town from the Transkei. Ironically, the benefits of the migration for access to health care were short-lived as her impairment was exacerbated by domestic violence, resulting in unemployment:

*I had an eye operation at Tygerberg and it became better...but two months ago, I was beaten up and injured by my husband in the same eye; I couldn't see anything with it. It is still blind even now. As the result of this I stopped working. My elder daughter was arrested for theft, and I am now looking after her daughter. Now the things that I live on are things that I am given by my neighbours. I am totally depending on them for food. My husband is still getting drunk and beating me up. I reported this matter to the street committee but they referred me back to my family [who] didn't come because it is too far away. (Philiswa, Nov 1998)*

There were other such stories of further impairment due to fragile networks. One woman with a stroke told of how her husband had beaten her because of her inability to complete the expected domestic chores. It is very likely that her impairment may have been caused by the beatings:

*My husband used to leave me alone maybe for a week and I didn't know where he was. And when he comes back he'd ask for food and when I didn't have food he would beat me up (Nolitha, Nov 1998).*

Even though Nonkosi received a disability grant, she experienced severe depression as a consequence of feeling helpless and trapped in a cycle of repeated abuse from her husband. A further gap in resources for protection occurred when she could not escape to the safety of neighbours either:

*I am a disabled mother who is getting a disability grant. I would be saying I do not have any problems if it was not for my husband. I cry on a daily basis. Whether he is working or not that is the same, he beats me day and night. I cannot ask for help from my neighbours because he will follow me and beat me in front of them. (Nonkosi, Nov 1998)*

The women experienced emotional drain in their everyday struggle to succeed in their small business initiatives. Their capacity to problem-solve was compromised by family dynamics. There seemed to be little recourse to justice or protection from physical harm that occurred when their partners were violent when under the influence of alcohol and/or drugs. Women reported repeated incidents of violence and abuse to community and neighbourhood structures such as street committees. But they did not get the help they needed, as these structures seemed to be ineffectual. The frequency of physical violence and abuse left women vulnerable to emotional trauma. The women drew on their own emotional resources often to the detriment of their mental well-being. Together with the loss of power, the different forms of exploitation left put them feeling at risk for further impairment related to mental illness and emotional distress.

The women's stories revealed a more subtle form of abuse than physical violence. They experienced **emotional exploitation** and a sense of rejection and ridicule in the denial of their needs. The women were on the receiving end of mockery, scorn and disrespect in spite of being a source of income and support for their households. There was also evidence of contempt and disrespect between siblings as a result of the impairment, which led to the risk of social isolation:

*The other thing is that of not being accepted in our families because we are disabled. They are wrong even by the things they are saying. They say 'I am not the reason why you are disabled'. You are then forced to go and live by yourself. (Sikelalwa, April 2000)*

Women who were also mothers of disabled children felt that they carried a double load as they experienced further rejection and ridicule after they acquired their impairment:

*We want to do as much as we can ... because we have our disabled children who are dependent on us. You find that in your family this child is not liked ...so you get problems since you are also disabled, you are no longer like the old mother. So that is different (Anna, April 2000).*

Arriving in Cape Town proved to be a mixed emotional experience for the women as they were faced with ridicule from their families:

*When I think about our load as disabled people, sometimes even if you were disabled long time ago, there are days when you feel you need support from the family. You need strength. If the family is throwing rude words at you, you can't succeed because you can't even think properly and your thinking is always about the bad treatment you are getting at home. (Sikelalwa, April 2000)*

Emotional exploitation also occurred when family members controlled or determined how the young women spent their disability grant. They felt there was little room to refuse to do household tasks in addition to being expected to do the domestic chores for visitors. One young woman, after being quiet and reserved in previous workshops, shared her distress:

*I identify myself with an animal with loads (crying). I do everything; I wash the clothes. They don't help me after school. I don't get the chance to go to church. A guy staying in our back yard wants me to do his washing as well. My mother and my sisters overwork me and my mother takes my disability grant. (Mavis, March 2000)*

Going to church was a significant and meaningful occupation for many women in these communities. Besides going on a Sunday they often attended women's prayer afternoons once a week, in addition to attending funerals or weddings over the weekend. It was heartening to observe how the older women provided support to the

younger women, and visited their mothers to speak to them about disability, as culturally, older women occupy different positions to younger women.

The women also experienced **financial exploitation**. They felt that they carried a burdensome load in their struggle to generate meagre profits from self-employment initiatives, in an environment of dire social disintegration and violence. They found that it was a struggle to succeed because family members were so dependent on them as a source of income. The load of responsibility to meet family needs became a burden. Nonzaliseko had sustained fractures of her leg in a road traffic accident. She struggled to make a profit in her small business, as her family didn't pay attention to her pleas:

*Most of [my family members] are drunkards so I look after their children. I also buy and sell meat but they eat the meat I am supposed to be selling... My relatives are the ones that are abusing me financially. I have tried to talk to them but to no avail. (Nonzaliseko, April 2000)*

Many women spoke about the load they carried from feeling responsible for paying the debts incurred by their children, adding to the sense of financial exploitation. Material poverty often meant that the women put the needs of family members before their own, especially where matters of health and well-being were concerned:

*You have to pay those loans when you get your money. They take clothes on account and they say, 'Mama I will help you pay it.' And they only pay once and you have to pay it on your own. If the person sees someone who is selling the clothes they ask them to come to me. The person will beg me to take something for him. They want jackets that cost R300. When you get home with your disability grant, the child tells you that she wants to go to the doctor, to pay his accounts...You are forced to give this money. This morning my son said, 'I'm going to the doctor, give me the money.' I also need the doctor but I haven't been able to go because I can't afford. (Siphokazi, April 2000)*

A typical story that showed the complexity of family involvement illustrated another dimension of financial exploitation by unsupportive families. Nondwe had not been to school as she became disabled at a very young age. She sustained a mobility impairment in the rural area where she stayed. Later, she decided to come to her sister. Her experience illustrates the barriers created from illiteracy and subsequent dependency on others for information:

*I then came to Cape Town to my sister and her husband. She is working as a domestic worker. I have not got a DG and I don't know why because she is responsible for everything. She does not tell me why social services are not responding to my DG application. (Nondwe, April 2000)*

The **loss of cultural traditions** where the male members of the family usually provided the support was evident in the stories. If their husbands had left them, the women had anticipated assistance from their male siblings. This help seldom materialised. The women described how they felt neglected by their male siblings who are

deemed responsible (culturally) for providing for the needs of their disabled sisters, especially if the father of their sister's children had left:

*I'm on my own. Since I became disabled my brother said, 'I will never provide for the children who have their father'. (Sikelalwa, April 2000)*

The converse of a cultural sense of responsibility also applied. The words of one woman expressed their intention not to burden the family members with the load of their impairment:

*My load at home is heavy... because I'm the head of the family. As a head of the family, my brothers and my child are all dependent on me... the family doesn't like you, but likes your money. (Nobom, April 2000)*

The sense of frustration and anger at the loss of support from male members of the family was exacerbated by the expectation that the women would provide for family needs as they received income from their grants. Some women, who had large families, felt financially exploited by their extended family who relied on them for support from the disability grant income. They had assumed the additional responsibilities of being providers as well as carers and nurturers. The women felt that there was little chance of success because of the dependency on them:

*I can't even bank some money because there is family. It's like all the time you didn't have this family and as soon as you get your [disability grant], you find that all your family is there. When you have problems they stay away from you and you keep saying 'I have a brother and he will never come and he is the one who was supposed to be helping me.' When he's working, he's not helping you. (Nobomvu, April 2000)*

Related to the theme of financial exploitation was that of **strained relationships** from the load of extended family responsibilities that many women carried. Women felt strained by having to meet different obligations of family members who were scattered in rural and urban areas. They struggled to make their business ventures a success, as revealed in Thandiswa's story:

*I wish I could have a business because R500 is little as all my siblings are dependent on me as our parents left us (died). So I need more money because I have to send some money to the homelands to give those who are here and I'm left with nothing. So I wish I could have a better business that will make me develop and be a better person amongst people. (Thandiswa, April 2000)*

The burden of the load that the women carried as mothers added to already strained relationships in the family. As mothers, the women felt responsible for preparing their children to have the emotional strength to face the world. The young women in the group gave another perspective on the strained relationships with their

non-disabled mothers, as they expected their mothers to provide for their financial support, which was not forthcoming because of the burden of poverty:

*As disabled youth, government is not providing anything for us. Even at home our mothers are dependent on the small businesses, which are not good because people don't have money. Our mothers and us are not on good terms. Even when we want things as youth, if you want to buy that, the parent tells you 'the food that I'm buying in the house is from my money and I'm supporting you'. So you end up not having any support. So the solution I wish there could be something that I can do to start up a small business (Small group, April 2000).*

The experience of the younger and older women exposed the constant need to change and adapt. Other women also felt the pressure to challenge stereotypes and prejudice about their abilities. This often strained relationships even further. The women recognised their responsibility as mothers to give children appropriate social skills and teach respect:

*Your child has a right to ask for things from you but you need to teach them to talk nicely when they are asking for something. They mustn't go and ask for something from other people because they think you can't do things since you are disabled. (Gloria, May 2000)*

Despite desperate family circumstances, the women maintained an honest sense of their reality. In her story, Vuyo describes her authentic concern for her mother's well-being and her desire to change the family circumstances, which caused her stress:

*I'm disabled. I have one arm working. My young brother is a taxi driver and my young sister is a drunkard. When she is drunk she abuses my mother who lives in [another township]. I get worried and I feel like if both my arms were working, I would stop her. I have my disability grant and I sell niknaks. I see myself straight like this line [basketball field]... until I die. I want to be straight to my mother and even with other people. (Vuyo, March 2000)*

In summary, women in impoverished communities such as Khayelitsha and Brown's Farm experienced disability as a burden, which was exacerbated by poverty. It appeared that women felt that '*All the loads are ours*' as they carried the responsibility of meeting family needs besides those of their own children. The spiral of violence and abuse sometimes resulted in further impairment, which exacerbated the women's sense of helplessness and powerlessness. This left them feeling as if '*Our souls don't rest*'. The few financial resources were stretched beyond capacity. Many stories painted a bleak picture of family dynamics as a consequence of continuous emotional and financial exploitation. The loss of cultural traditions contributed further to strained relationships in the family. They were left despondent about achieving success in their business endeavours.

For the women to experience physical and emotional well-being, the abuse and exploitation they experienced would have to change dramatically. The process of storytelling and reflecting on actions offered hope, as the



women gained from the positive self-images and strong role-models within the group. The process helped the women to understand their own situation and find solutions or ways to resolve it themselves.

### ***Disability as a gain***

In spite of the burden of disability that some of the women were caught up in and the vicious cycles of poverty and disability they had to deal with, the research also revealed the experiences of other women who often had a determination and vision that prevented them from giving up. These stories revealed **disability as a gain**, as seen in the words of the women's of "*Doing a little with a lot*":

*With the grant that I get, I am able to provide for my family and support them. I can handle my load. We know that in our families we are breadwinners even though we are disabled. All the loads are ours. We feed our families ...we are even able to buy clothes for ourselves and we can carry that kind of load. You buy chips and sell and buy beef stock and put it in your food and eat nicely. (Bulelwa, March 2000)*

The women's resourcefulness was seen in the many stories of **optimising their disability grants**. While the impairment may have a financial impact on the family, social security grants, such as the care dependency and disability grants (DG), that the women were able to access proved to be the sole source of income. DGs gave them a role of provider in their family again as it enabled them to meet basic family needs for survival. DGs were instrumental in enabling women to take the first steps towards economic empowerment and social integration. The grant quickly became seed money for small business initiatives, which helped the women with the load. From the many stories told in small groups, it was clear that DGs were not mere handouts that fostered dependency, but a vital means to self-empowerment. One woman expressed what seemed to be a common experience of the others as she recognised her ability to support herself by being self-employed, especially as receiving her DG was precarious:

*I get the grant but I wish I could help more with getting apples or oranges to sell them so that my load would be lighter. (Cynthia, March, 2000)*

*We are disabled [but] we can do business and handwork. We don't just sit, like myself at home, I'm making dolls using the small pieces of material. If it's big material I make duvets and pillows. I don't just sit. My grant gets stopped sometime, but I tell myself I must try so that I can get something to eat. Like now I don't have anything to eat and I don't know what I'll do. But I do make those dolls and go and sell them so I can go and buy something to eat. (Edith, June 2000)*

**Voicing their needs** was another prominent finding, as it was a strategy that could reinforce self-reliance as the women actively sought advice and assistance in carrying their loads. The women voiced their vulnerability since the introduction of a policy in 1999 that necessitated annual re-evaluation of their DGs. Such a measure would mean that their one source of income was not guaranteed. A common request was for advice related to actions they could take to protect themselves against continued domestic abuse and financial exploitation in the families. The stories suggest that the women actively sought advice on how to access resources to ensure success in their self-employment initiatives and entrepreneurial development:

*I have four children and I do not know what to do and where to get help... Is it possible that they will build houses for the disabled only? I cannot see a future and success with the person I am staying with. Please can I talk with you after the meeting?* (Nonkosi, November 1998)

*Fortunately one of my brothers was in Cape Town. I also got my disability grant so I could buy and sell meat. I have tried to talk to family members who are eating the meat but to no avail. I would like to speak to you after this meeting to find if there is anything that I can do to relieve me from financial exploitation by family members who eat the meat I want to sell.* (Nonzaliseko, November 1998)

Many women asked for assistance to investigate why they did not get DGs. Such incidents were not rare where power in the form of control of the DG was in the hands of family members who accessed the grants. The women were left with little recourse to justice, as they did not have adequate understanding of how to access the public system from public health practitioners. The women appreciated any feedback on the progress and outcome of their disability grant applications.

Despite her impairment, one of the women found the strength and courage to voice her feelings and needs to her family directly, so as to correct the perception of dependency. She appeared to have exhausted the possibilities of accessing social security:

*I tell them, 'You are all dependent on me and I'm not looking after anyone else except my children.' If my children do something wrong in the community, I stand for that on my own. The government books are full of my signature. If you think you are going to look after the family you'll end up with nothing and by the time you wake up, it will be sunset.* (Monica, March 2000)

For some of the women who had moved from rural areas and were staying with family members, the sense of acceptance and support from family members was appreciated, in contrast to other's experiences of exploitation and violence in their families. **Fostering reciprocity** was a strategy that enabled the women to manage the loads of poverty and disability. The readjustments were made more feasible as there was potential to foster reciprocal support. Contrary to popular belief, the stories revealed how the women were prepared to carry the responsibility for their impairment. The women could often reciprocate as they provided a source of income from their DGs. Following a traffic accident as a pedestrian, Nonsaliseko and Vuziwe found reciprocity from the multiple sources of support that they received, as they were able to meet family needs:

*Fortunately one of my brothers was in Cape Town so I came to him. I was sent to [a secondary hospital]. On my discharge I had to use a wheelchair. Fortunately I got my disability grant. Everybody in my family depended on me* (Nonsaliseko, Nov 1998).

*My parents are in [a town in the Eastern Cape]. I stay with my brother. My other brothers are there, but it's as if they are not there because I'm doing everything by myself and I'm not dependent. I go to places like Federation and even in the township there is no one who feels for me and says, 'Shame let me do this for you.' They treat me like an able-bodied person. Now I identify myself with an elephant, as I'm the one "engasindwayo ngumboko wayo" – [a proverb saying the elephant's trunk is not heavy for it, meaning each person can handle her load]. My disability is mine; I can't place it on other people, it's mine. As this elephant, I'm carrying my child and myself. Even my brother is using my things, but he doesn't give me even a cent.* (Vuziwe, April 2000)

Some women had met the cultural expectations such as having children, building up a home and marrying, showing their desire for an ordinary family life:

*They get married and we also get married. They get children and we also get children and we also go to work just like them.* (Small group, April 2000)

For some women, the desire for an ordinary family life involved the need to find a house in which to create a home as an integral part of fostering a healthy and balanced family life:

*Our neighbours have houses and we also have them. Even when they buy furniture, we can buy furniture.* (Small group, April, 2000)

In summary, the women showed their resourcefulness by '*Doing a lot with a little*' in the way that they optimised their DGs, voiced their needs and fostered reciprocity. The women were proactive in voicing their needs for assistance when it came to dealing with domestic violence, financial exploitation, economic empowerment and accessing resources for development. While the women used their grants as seed money for informal trading, they had other aspirations for entrepreneurial development. They voiced a need for business literacy to learn how to maximise their DG to increase their family income! They adopted strategies to manage the multiple responsibilities they carried constructively with few resources at hand.

### Cycle 3 *There are so many things happening on our lives: at a community level*

Cycle 3 explored the disabled women's experience of interfacing with the community. The dominant theme from the findings emerged as "*There are so many things happening on our lives*" (see Table 6). The "*many things*" had two dimensions: on the one hand the women experienced **imposed boundaries** as barriers in the community within which they lived. On the other hand, they found ways of **extending boundaries**, which became strategies for human development. Substantiation of the main theme of Cycle 3 follows with reference to each of the two sub-themes and supporting categories.

**Table 6: Themes related to personal experiences at a community level**

THEME	SUB-THEMES	CATEGORIES
<i>There are so many things happening in our lives.</i>	<b>Imposed boundaries:</b> <i>So we gave up.</i>	<ul style="list-style-type: none"> <li>• Insufficient understanding of disability issues</li> <li>• Poor dissemination of information</li> <li>• Being poor</li> <li>• Missed opportunities in schooling</li> <li>• Publically marginalised</li> <li>• Personally marginalised</li> </ul>
	<b>Extending boundaries:</b> <i>Bettering our lives.</i>	<ul style="list-style-type: none"> <li>• Engaging different sectors</li> <li>• Overcoming isolation</li> <li>• Enhancing skills development</li> <li>• Gaining access to gain</li> </ul>

#### ***Imposed boundaries***

This sub-theme revealed a range of barriers the women experienced as they interfaced with the community. Boundaries were imposed when their participation and freedom to make choices was restricted because of gaps in resources. "*So we gave up*" expressed the frustration and despondency that they felt in facing the attitudinal and structural restrictions imposed by the social and physical environment.

Many women's stories revealed **insufficient understanding of disability issues** by health and social service staff. Earlier accounts (in Cycle 1) revealed how mismanagement of different impairments by health professionals, especially poor monitoring of medication for epilepsy, had hindered the ability of some women to engage in everyday roles and activities. Ignorance about disability by some health and social services practitioners meant that women often found services attitudinally inaccessible and unsupportive. Siphokazi's story was a powerful illustration of how insufficient understanding of disability issues obstructed her access to appropriate health care. Siphokazi was angry as she recalled her experience of interactions with public health practitioners related to her impairment:

*One morning I went outside I felt something sharp on my heel and I could not get up. My hands felt like they were breaking and [I was] sent to [a day hospital at primary level]. They could not help me and they sent me to [a tertiary hospital]. The doctors did not know what I had and they asked me if we have a history of TB at home or high blood pressure. I told them there is no history at home. I asked them what was my problem and they said they would amputate my leg. I didn't allow them since I was asking them to tell me what was wrong with my leg. The doctor was very angry with me and he said he was giving me one more day. I went home and I was in very bad pain. After some time two CRWs came looking for me. Initially I did not trust them and I did not tell them my real home. But later I told them my name.* (Siphokazi, Nov 1998)

While many practitioners may not have intentionally blocked opportunities for dialogue about the choices facing the women regarding their health care, their approach was often perceived as abrasive, thereby increasing the women's sense of imposed boundaries. Although Siphokazi asserted her right for information before consenting to an operation, she felt that the doctor penalised her for making a choice that differed from what he recommended. This left her vulnerable to not receiving the necessary treatment. The unfolding of her story reflected the poor communication between the women and practitioners working at primary care level in the public health services, namely, doctors, nurses, rehabilitation therapists<sup>13</sup> and social workers. Mistrust about the intentions of health practitioners created a further boundary to health care.

Bulelwa walked with the assistance of a caliper and crutch following an impairment acquired as a result of a road traffic injury. She told her story:

*A truck knocked me down while I had my baby strapped to my back. I was taken to a secondary hospital for treatment of my injuries. I refused to have my leg amputated because I still had hope of using my leg again.* (Bulelwa, June 1998)

The courage of women such as Siphokazi and Bulelwa, gave hope to other women that the imposed boundaries due to insufficient knowledge and understanding of disability issues, could be overcome. They came to understand that they had a right to the dissemination of appropriate information in order to make informed decisions. Bulelwa, for example, had not felt intimidated to pursue a line of questions with practitioners so that she was able to make informed decisions.

But Siphokazi's sense of vulnerability related to the imposed boundaries continued as she battled to obtain a disability grant (DG) because of **poor dissemination of information** between the different services. It resulted in wasting her time and resources. She continued to experience intimidation in interactions with practitioners in the community health centres. She had a very sad look in her eyes as she shared with the group her depression and loss of hope. Exposure to these imposed boundaries eventually took its toll on her resilience:

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<sup>13</sup> I have chosen not to differentiate between occupational therapists, physiotherapists, speech and language therapists and audiologists, as community members seldom mention these differences.

*The social workers at the day hospital say, 'What is [the DG] for because you are young?'... I went back [to the social worker] and he said I must go back to my doctor so that he can write a letter for DG. The doctor disagreed and said if I agreed to cut my leg I would be getting DG. So I gave up and I'm staying with my children and I only do what I'm able to do. (Siphokazi Nov 1998)*

Nomalizo found herself in a similar position on her discharge from hospital, revealing that the dissemination of information related to the process of applying for DGs was poor:

*My disability is a hunchback. I came to Cape Town with my mother because she was also sick. She died at the [a tertiary hospital] very soon after our arrival in Cape Town. I have got three children that I am looking after, two are mine and one is my mother's. I am not working and I am not getting a disability grant. I applied for a disability grant in 1995, but until now I haven't received anything and nobody knows why. I live by getting food from neighbours and friends. My wish is that I would like somebody to investigate why I didn't get my disability grant. (Nomalizo, Nov 1998)*

The combination of insufficient understanding of disability issues and poor dissemination of information about the process they should follow meant that the women felt constrained in their ability to move forward on their own. **Being poor** imposed further boundaries to accessing health and social services. Ironically, opportunities to access social security were hampered due to women not having money:

*I have drawn a person with a little girl next to her to show my mother and me when we were still working on the farms. But my mother died and I came to Cape Town. I had a stroke and I was sent to [a secondary hospital]. I was given a letter when I was discharged to take to the Welfare Department for a disability grant, but I didn't go there because I didn't have money ... the letter is still with me at home. (Nomonde, Nov 1998)*

Nomzamo's story showed how life was good and then changed when she sustained the impairment. She was unable to access resources for rehabilitation due to financial constraints:

*I drew a flower because I thought I will be a flower for my parents and everybody at home loved me at that time. But unfortunately I was in a car accident. I fell and I broke a leg and a thigh. It was difficult for me to attend treatment because there was no money. (Nonsaliseko, Nov 1998)*

Many women felt responsible for the schooling not only of their own children, but also the children from the extended families. This financial responsibility imposed further boundaries to their development. The women gave numerous accounts of their despair that their children were not receiving an education due to poverty:

*My mother's child is seven years old now and supposed to be at school, but I can't afford to send him to school.*

*I have got three children that are not mine and two of mine. This causes problems because I don't have enough money to send these children to school. (Nonsaliseko, Nov 1998)*

The women felt pressure to do better than non-disabled mothers despite their impairment. Such imposed pressure sometimes meant that they contributed to the well-being of their neighbour's children even if it meant that they incurred a debt, creating vulnerability to stress from deeper material deprivation:

*[I] buy clothes for other people's children and even when they are sick you have to borrow money for their children. Sometimes you borrow this money from outside (Bulelwa, March 2000).*

Another imposed boundary associated with being poor was **missed opportunities in schooling** leading to high rates of illiteracy. Many women identified the lack of money within the family as the reason for not being able to complete schooling rather than as a consequence of their impairment. A young woman of twenty two years shared how she was disabled at the age of fourteen years when another child in her community beat her up. She was forced to leave school and now felt frustrated about lack of education. Her sense of imposed boundaries was aggravated because she has been unable to find a job, reinforcing her low self-esteem. Her desire was to go back to night school or do a computer course:

*I dropped out of school because of money problems. I would like my children to go to school and not be uneducated like me, but I had no money. So I was really sad and didn't know what to do. (Nomalizo, November 1998)*

Returning to Siphokazi's story, she shared the tensions of her own poor schooling and struggling to cope with her disabled son, as she had little understanding of his condition. Her child was sent home from school as the teachers said they could not teach him anything because he was disrupting the class:

*Another problem that I have is that of my son who is mentally disabled. I cannot explain what I'm going through because of Sachumzi. Even if I beat him he does not have any feelings for pain and he just laughs. I've taken him out of school because he beats others at school. When the teachers punish him, he laughs. He also likes rotten food, which he eats from the dustbins. (Siphokazi, Nov 1998)*

The women experienced a sense of being **publicly marginalised**, as public transport systems were both the cause of impairment and an imposed boundary to access opportunities for social and economic empowerment. The majority of impairments resulted from road traffic accidents, which left the women feeling vulnerable when using public transport. One woman was involved in a taxi accident as a passenger. This resulted in the amputation of her lower limb. Her husband, who was the taxi driver, left her following the accident. He had not given her money and refused to go to her parents to apologise. Kholeka was a pedestrian when she was hit by a bus and fractured both legs. Cynthia who had a stroke in 1991 used to sew clothes, which she sold to make a living. She felt marginalised from social activities because of inaccessible transport:



The experiences of some women in **engaging different sectors** in understanding disability issues reflected both barriers and opportunities for fostering development, as reflected in earlier stories. Nozuko's story illustrated how the nature of impairment interconnected the different sectors such as health for initial medical treatment, social services for disability grants, labour for business skills development and DPOs for advocacy and lobbying for rights and opportunities:

The women pursued ways to engage in productive development. They realised that effective referral systems between public-private health practitioners would provide them with a wider range of options for better health care to enable them to work again:

*I would like to do something to help myself. But my arms and hands become stiff ...I have been attending the [a district hospital providing primary level care], but I don't get well. I am going to request my doctor to transfer me to some specialist because I can't do anything with the problems that I have in my legs and my arms.*(Nonkosi, Nov 1998)

Many stories reflected the direct benefits of community rehabilitation workers (CRWs) being part of a comprehensive team approach with a well-established referral and support systems across the different sectors, as they were able to actively extend the boundaries that were experienced by the women as barriers.

*I have drawn something like a heart ... I was burnt in my shack five years ago. I was helped by my neighbours to get out, but my hand got burnt when I was trying to extinguish the fire. I was sent to [a secondary hospital] and stayed there for four months. On my discharge I couldn't handle things very well with my hands. I didn't get my disability grant. I started selling beef as I could get people to bring me to the abattoir, but this didn't go well because [neighbours] cheated me. At the same time I was diagnosed that I had TB. For five months I attended treatment, which was stopped. Now what I would like to ask from the CRWs that they continue to give me food parcels, because my hands don't work.* (Nombulelo, Nov 1998)

Nombulelo's story reveals the complexity and nature of the CRWs' role in creating a bridge to resources in order to integrate disability issues into social and economic development effectively. In many ways, the CRWs seemed to be mediators of the different dimensions of vulnerability experienced by the women, as they interacted with numerous NGO service organisations, public health services and community development practitioners.

The CRWs seemed play an important role in easing the stigma related to the impairment, which helped the women's vulnerability in **overcoming isolation**, as the CRWs helped to extend the boundaries between the women, their families and the wider community:

*It's better for those who are getting their grant ... Even when you are sick, it's only when the CRW comes that you will be identified and it will be seen that you are sick. You have to send a child to your family member to tell them that you are sick. Sometimes when you come they just close their doors and tell you they are going to town. (Nontsidiso, Aug 2000)*

In this way, home visits by CRWs were cited as a means of emotional support as it encouraged the women to overcome their isolation. The women were encouraged to participate in meetings and workshops with other disabled people. The support of CRWs often helped to heal depression and anxiety.

*I became disabled in 1992. I felt very sad. There have been so many things happening in that house and I used to cry. But the day when CRWs came, they supported me... When I'm in workshops I see myself as a woman with dignity. I never believed in myself. (Siphokazi, March 2000)*

The CRWs took personal perceptions of the women related to exclusion seriously. In response, the women also challenged the CRWs to let them be the role-models for the young disabled children in the community as a way to establish positive reciprocal relationships. Such reciprocity in roles contributed to understanding the dimensions of vulnerability and in securing ways of addressing them.

The CRWs contributed to **enhancing skills development** of the women. They accessed training and entrepreneurial opportunities to bolster the efforts of the women who were selling sweets, ice cream, or sheep's heads. Access to skills development opportunities was particularly significant as many women only had primary school education with associated low numeracy skills. With the political transition in South Africa, the women were motivated to further their education and were seeking ways to develop new skills or to take collective action to help improve their situation and achieve their desires.

Nomonde realised that the CRWs would be able to help her to access adult education classes:

*I then came to Cape Town to my sister and her husband. She is working as a domestic worker and I would like to go to school since I am still twenty one years old. I'm going to ask a CRW to help me find a school that I can go to. (Nomonde, Nov 1998)*

The women recognised the importance of sending their children to school as it gave some assurance of a better life than they had lived. It was paradoxical that while the costs of schooling was a burden, the children also provided the motivation and drive for women to enhance their skills in order to succeed. Earlier stories showed the sense of imposed boundaries due to no money, which appeared to increase when a woman was a mother of a disabled child as well. Siphokazi lived with her four children in a wooden shack. Her story shed light on how her struggle to meet obligations of schooling was assisted by the CRWs extending boundaries by accessing resources:

*When [the CRWs] arrived I was with my children and they were all not at school since I could not afford. One of the CRWs told me that they would try something so that my older son could go to school and that happened. (Siphokazi, Nov 1998)*

The CRWs also provided a means for **gaining access to resources** as a way to tackle the imposed boundaries the women experienced. In addition, the practical, hands-on approach of neighbours who extended the boundaries through provision of food security often instilled a sense of gratefulness and security in the women. Such help was often the only means of support and survival, which exposed the depth of vulnerability the women lived with. Many women depended not only on their neighbours, but also on CRWs as a means to extend boundaries related to their survival, as they were able to access food or food parcels from them. Some practitioners may perceive such support as dependency, yet it was all that a woman who was blind in one eye knew:

*The candle symbolises me as a spark at home before I got disabled. Now the things that I live on are things that I am given by my neighbours. I am totally depending on them for food. (Philiswa, Nov 1998)*

Support and interdependency helped to extend boundaries towards achievement of development goals. Kholeka started a small business brewing beer with her disability grant. But she knew she could not rely solely on this, as there was no guarantee of long-term sustainability. Her vulnerability was evident in her request for knowledge and skills on how gain access to support in order to progress:

*Then I applied for a childcare grant for my children. The day I received the grant, mine was stopped. Fortunately I received money for the bus accident. It wasn't much, but my mother said before she died I must take it even if it's little. I am still brewing the beer, but I would like to do something better like sewing. But I don't know where to start. (Kholeka, Nov 1998)*

In summary, the stories from Cycle 3 provide evidence that the women were creative in making ends meet, by extending boundaries together with CRWs, who provided a bridge through information and different forms of support. These boundary extensions ranged from securing food from neighbours, to DGs, schooling and enhancing skills development to ensure the sustainability of their small business initiatives. The findings showed the vulnerability experienced in coping with impairment and disability and the fragile balance in meeting the physical, psychological and emotional needs in the family. Thus the women have been able to gain access to different resources and social networks for support in small, significant ways. Such support helped the women find ways to manage the many things that were happening in their lives.

## Part 2

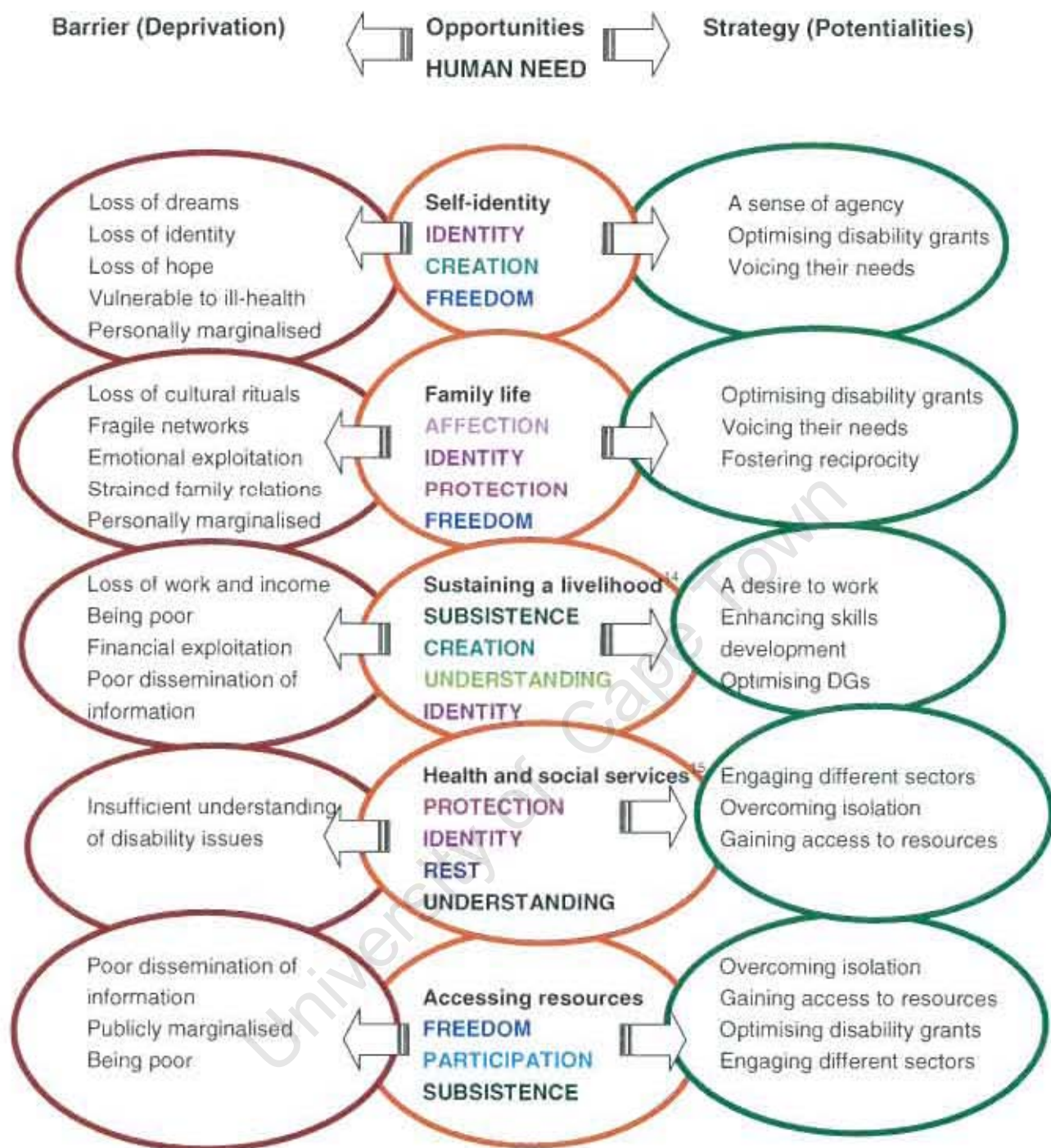
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### THE COMPLEXITY OF DISABILITY: DISCUSSION

#### Introduction

The findings of the previous three iterative cycles in Part One of the chapter describe the barriers to human development experienced by the women from three perspectives: individual, family, community. The strategies used in meeting human needs at the same three levels since acquiring their impairment are demonstrated.

This second part of Chapter Five addresses the first objective of the study, namely, to discover the factors that hinder and foster the human development of the women. The discussion presents the interaction between the facilitators' thoughts and an interpretation of the findings with different sources of literature. The findings raised an awareness of the complexity of disability in impoverished contexts by signalling the *deprivations* (identified as barriers) and the *potentialities* (identified as strategies) of the human needs of disabled women (Max-Neef, 1991). Congruence emerged between the human needs and the opportunities for participation (UN, 1994). The dynamic interplay between opportunities for development and the human needs of disabled women that were identified in the women's stories from the findings in Part One is illustrated in Figure 8. The overlapping circles depict the movement that occurs laterally, as well as upwardly and downwardly between the different opportunities and needs. The diagram illustrates how an opportunity may address more than one human need simultaneously. *Deprivations* occur when human needs are not satisfied and conversely, a *potentiality* indicates that human needs are satisfied. Literature that explores the cultural, gendered and political dimensions of the women's experiences within their local context is presented (Denzin and Lincoln, 1998b). The chapter culminates in the planning step of the action-learning cycle, so as to identify critical suggestions for further action. The actions were either addressed in the subsequent phases of the study or highlighted areas for further research beyond this study.



**Figure 8: The push-pull tension between human needs and equalising opportunities in human development for disabled women.**

<sup>14</sup> Employment, social security and income maintenance

<sup>15</sup> Medical care; Support services. Rehabilitation, Public awareness



## Deprivations and potentialities

The stories clearly depict how social and economic rights, which refer to the right to adequate housing, welfare, education, health care and a clean environment (Jacobs *et al.*, 2001) were sorely underprovided for the women. Such deprivation, as seen in the women's lives, reflects the oppressive nature of both poverty and disability. The potential to achieve these rights is, however, mitigated by social realities such as structural violence, poverty and political power (Coleridge 1993; Meer, 1998; Ramphela, 2001). Generally, violence and abuse are endemic and experienced in the form of wider social disintegration (Ramphela and Wilson, 1989). The struggle to survive the different forms of deprivation and the potential to succeed appears strongly related to and involves individual, family and community dynamics. These dynamics correlate with international concerns about the needs of disabled people. They substantiate the relevance of a human rights approach aimed at the inclusion of disabled people into the mainstream of society. Equalising opportunities would contribute to breaking the vicious cycles of deprivation, identified by Chambers (1983) as a consequence of poverty, physical weakness, isolation, vulnerability and powerlessness. Stone (2001) adapted the deprivation trap to include impairment and disability (see appendix 8). The complexity of disability will be discussed in five critical areas (see Table 7):

- Self-identity: loss and agency
- Family life: pain and pride
- Sustaining a livelihood: missed opportunities and active contributors
- Health and social services: ignorance and CRWs as buffers
- Access to resources: marginalised and potential to be free

**Table 7: Summary of five critical areas related to the complexity of disability**

Deprivations (Barriers)	Disability (Standard Rules)	Potentialities (Strategies)
Loss and isolation	Self-identity (Rule 9)	Agency
Pain	Family life (Rules 9 and 12)	Pride
Missed opportunities	Sustaining a livelihood (Rules 6 and 7)	Active contributors
Ignorance	Health and social services (Rules 2, 3, 4 and 8)	CRWs as a buffer
Marginalised	Access to resources (Rules 1 and 5)	Potential to be free

### Self-Identity: loss and agency<sup>16</sup>

According to Giddens (2001:698) self-identity is “the ongoing process of self-development and definition of our personal identity through which we formulate a unique sense of ourselves and our relationship to the world around us”. One picture that emerged was how impairment and ill health result in a sense of

<sup>16</sup> Relates to Rule 9: Family life and personal integrity

powerlessness and hopelessness at an individual level because of the losses experienced. These losses cause a ripple effect at the family level. The women typically found themselves in situations at community level that seemed hopeless because of the inadequate health and social services. The closing of sheltered workshops at a community level impacted on losses at an individual level. The losses illustrated a complex interaction between the experience of disability and race, gender and poverty as forms of oppression. Vernon and Swain (2002) found that black, disabled women in the UK who experienced multiple oppressions were not able to identify a single source as the root of discrimination. Thus practitioners are confronted with the tensions of balancing the ideological associations between impairment, needs and care with that of disability, exclusion and rights (Priestley, 1999). According to Nosek *et al.*, (2003), social isolation was found to be the most common secondary condition associated with any primary impairment. They showed that disabled women experienced problems associated with low self-esteem such as depression, unemployment, social isolation, limited opportunities to establish satisfying relationships and emotional, physical and sexual abuse. A similar situation was found in this study: the experience of impairment led to a sense of self-pity, self-imposed isolation and marginalisation. Stone (2001) depicts impairment and disability as part of the vicious cycle of poverty. The women in this study recognised that they undermined themselves and were undermined by others, leading to experiences of depression and anxiety. These occurrences were similar to problems reported in other studies in South Africa, Britain, Canada, the United States of America and Sweden (Mda *et al.*, 1996; Driedger, *et al.*, 1996; Barron, 1997; Thomas, 1998; McGrath *et al.*, 1990 in Nosek, 2003). The commonalities in the experiences of these women with other women favour the inclusion of women in mainstream development.

In their stories, the influence of roles on self-esteem was evident in the way the women described their inability to complete familiar tasks and activities associated with an ordinary life. Their low self-esteem and sense of helplessness revealed their own attitudes and fears. Their perception appeared to be reinforced by gendered roles imposed at a societal level. Thus self-esteem and gender could be negative satisfiers and barriers to human development. Nosek *et al.*, (2003) presents findings of a study in the United States of America that concurred with the experiences of dependency, as they found an interconnection between women's losses and their self-esteem. They claimed that losing the ability to perform the activities of daily living could threaten one's sense of self. Both Thomas (2004) and Reeves (2004) have identified that such feelings relate more to the psycho-emotional responses to impairment than the physical impairment itself. Thomas (2004) concurs that the psycho-emotional effects of impairment would be a hindering factor to social and economic development. The women's lack of confidence and low self-esteem following their impairment revealed human poverties of identity and understanding heard in frequent statements of "*I don't know*". These poverties had ripple effects on the other human needs, such as subsistence, affection and creation. The interconnections found between the losses and imposed boundaries were similar to Nosek *et al.*'s (2003) study. They found that women were disconnected and isolated from sources of support systems and intimacy, employment opportunities and health promotion because of the environmental barriers and the absence of positive messages and opportunities they encountered. A consequence of a loss of self-identity was that many of the human needs remained unmet.



By contrast, a positive self-identity advanced the sense of agency and the ability to effect change in their lives. The potential for development was revealed in their sense of agency that extended to their desire to work and to foster reciprocity. Both Bauman (Bauman and Tester, 2001) and Max-Neef (1999) feel strongly that these needs could become the resource for action, when individuals choose to act collectively to change the root causes of their problems. Pivotal in the process of social change is that the women should feel good and be sure of their own value. Coleridge (1993) has argued that a healthy self-esteem gives the power to begin changing circumstances through a combination of practical action and advocacy. Thus self-identity was a positive, synergistic satisfier in situations where women were able to generate change through their sense of agency and desire to work. They were able to optimise their disability grants and voice their needs. Such innovativeness helped to foster reciprocity so that a space was created to nurture their sense of self, well-being and wholeness. Bauman (Bauman and Tester, 2001) recognised the tension between beauty and humiliation: beauty was the expression of human ability to make and think a different world; humiliation was the piling up of necessity over possibility, whether from physical humiliation that arose from suffering or the material humiliation from poverty. Both these aspects were present in the lives of the women.

### **Family life: Pain and pride**

The stories cast light on the ordinary, everyday occupations of disabled women, in the home and informal trading, balancing and juggling responsibilities while getting little respite from the daily grind and struggle against poverty. The image of a donkey carrying a load depicting their family situations illustrated the two sides of the experience: some women found the family responsibilities painful and burdensome, while others found them an achievement and source of pride (see Cycle 2). Cornielje (1999) found a prevalence of this double role of women in rural areas in the North West Province in South Africa. Many women in the study were single parents who still carried the responsibility for other children besides their own. Pahl (1988 in Read, 2000) spoke about a similar picture of mothering in Britain. Generally, mothers have been seen as active agents of history, shaping cultures and creating cultural and moral values for themselves and others. Read's (2000) differentiation between motherhood as the social and legal status, and mothering defined as the caring and nurturing activities associated with motherhood, is meaningful to this context as well. The women's accounts of mothering reflected contemporary accounts of motherhood more generally (Meer, 1998). The women accepted the responsibility for protecting, maintaining and promoting health and well-being within the household, as they juggled the different roles of sibling, daughter and partner (Doyal, 2003).

The women in this study had moved to urban areas in search of work and better health and social services, which was common amongst other women in South Africa (Meer, 1998; Taylor and Conradie, 1998). Many women had family members who remained in the rural areas of the Eastern Cape, resulting in a loss of family support and subsequent human poverty of affection and protection. In South Africa, migrancy has been associated with a sense of dislocation, as migrants have to re-establish support while often trying to meet the primary human need for subsistence (Ramphela, 2002; Ramphela and Wilson, 1989). Barberton (1998) classified obstacles of location related to where poor people live as a determinant of participation.

Traditionally, in African culture, if the husband left or died the male family members were the breadwinners and financial providers for family needs (Meer, 1998). Ironically, the traditions were often reversed in situations where brothers and children were dependent on the women who became the providers, carers and nurturers. Other studies on South African experiences (Haricharan and Rendall-Mkosi, 2002; Lorenzo and Cloete, 2004; Ramphela, 2002) confirmed our findings: women were often single parents, who carried the load of responsibility to meet extended family needs by using income from their DGs or profit of small businesses. The loss of the father figure in parenting was attributable as much to poverty as impairment.

Being vulnerable to violence spiralled in the form of physical abuse, as well as financial exploitation within in their own homes. The situation was exacerbated where the husbands were unemployed and engaged in substance abuse. Unemployed family members put a strain on the women's abilities to provide for the survival needs in the family. In her study of youth in the same area as this study, Ramphela (2002) describes complex family relationships, pressed by the scarcity of resources, both emotional and financial. She notes that the meaning of family in such contexts was fluid. Housing and the home situation was an area of desperation for some of the women. This shortage meant that their right to have a family home (Rule 9, UN, 1994) was violated because of the impoverished conditions in which they lived. Meer (1998) argues that women, generally, carry the load of physical violence and abuse alone. She found that neighbours generally saw domestic violence as a "hidden crime", as it is viewed as a private family matter, between a husband and wife. Furthermore, the fragmentation and disempowerment that the women experienced, whether disabled or not, as a result of violence and trauma was characteristic of impoverished communities in South Africa (Buchanan and Hilton-Smith, 2004). Fragility related to their impairments and family networks exacerbated their vulnerability to physical and emotional ill-health (Duncan, 2004; Swartz, 2004). Fourie *et al.*, (2004) found that people living in poverty in previously disadvantaged communities in the Cape Metropole spent most of their time struggling to meet the survival needs, such as food. Other studies confirmed that people in impoverished communities do not have enough space for time-out (Meer, 1998; Taylor and Conradie, 1997; Watson and Lagerdien, 2004). The women mentioned very little about how they meet their human need of rest, as they had little time and energy left for any personal interests. They had limited choices or alternatives for meeting family needs. The stories echoed the words of Coleridge (1993) about life lived on the edge of survival, as highlighted in the literature review.

Even though *Standard Rule 9* on family life and personal integrity makes provision for the member states to address the burden of disability discrimination and abuse attributed to violence inherent in the negative attitudes existing in families, the women found little recourse to justice in poverty-stricken situations. Such situations were exacerbated when there was a disabled child in the family. The women also bore the consequences of violence in the form of emotional taunting. Read (2000) quotes a study in Britain by Atkinson and Crowthorpe (1995) about the bullying and teasing faced by siblings of disabled children at schools because of their brother or sister's impairment. Ingstad (1995) found responses to disabled people in Botswana who were taunted and teased and laughed at, similar to the sense of rejection and ridicule that the women experienced. Other studies have revealed the strained relations in families as a result of emotional



and financial exploitation. Beresford (1995 in Read 2000) found that in the UK support from extended families was important and an unfavourable reaction from a family member toward the disabled person could be very distressing. The stories illustrated how the women were primarily emotionally connected to their cultural roots first. They aspired to having children despite their impairment. It may also reflect the pressure they felt related to gender roles and cultural expectations that all women would bear children (Meer, 1998). The need to understand and appreciate the consequences of the loss of family and cultural traditions in the equalising of opportunities for development is supported by Mazwai (1999:419) who claimed:

Our customs and other indigenous knowledge systems [will be] the instrument of socio-economic development, ...freedom ... is the right to self-determination and the right to a better life.

It was important to recognise and appreciate the sense of pride that the women experienced in facing and overcoming the struggle to succeed. They felt that they were "*left with nothing*" after meeting different obligations within the family. There was a pervasive sense of powerlessness related to the struggle to have enough money for the children's needs, a tension that Ramphela (2002) uncovered amongst many families in the same area of this study. It was clear from the stories and experiences that disability grants enabled the women to manage the responsibilities of mothering as providers and nurturers. Their stories showed that such pride was often coupled with the tension being the only source of income in the family. As such, it challenged and changed the perception of the women being passive and dependent. Monica's experiences (see appendix 9) echoed the sentiments of Benn (1998, in Read 2000:78) about being the mother of a disabled child:

Motherhood is not only drudgery. Being a mother is calming, it is moving; it is enlightening; it is fun... ordinary pleasures ... it is a different sort of challenge [to employment], a place where a variety of values can be expressed and maintained.

The experiences reflected the importance of family in Xhosa culture (Broodryk, 2002; Tutu, 2004). Tutu (2004) argues that it is in the family that children learn about the nature of the world, power and justice, peace and compassion. The family is where oppressive or liberatory behaviours are first experienced and learnt. It is in the "humdrum, ordinary, unexpected and unlikely places and people" that change occurs (Tutu, 2004:95). Ingstad (1997), writing on CBR in Botswana, speaks about the caring role that a family needs to adopt when someone becomes disabled. The findings in this study suggested the opposite; in fact the women continued to play the primary provider and nurturer role. So, paradoxically, the provider role effectively dispelled the myths of laziness associated with inability and dependency. It challenged the myth of women being dependent passive victims. Both Priestley's (1999) and Thomas' (1998) work indicate that disabled people are active agents, which supports this finding. Bauman and Tester (2001) have commented that people have potential and choice in determining their world. Similarly, writing about mothers of disabled children, Read (2000) provides evidence that they were able to act on the world as opposed to be merely acted upon. They were active, contributing citizens who coped under very demanding situations, similar to the creativity and a dogged determination in seeking solutions to problems (Read, 2000). Such agency could

be explained by Max-Neef's (1991) claim that human needs become a resource and motivation that mobilises people to find strategies to overcome the pressure of family needs. The women experienced vulnerability and valued support. Thus experiencing vulnerability as strength depended on the nature of support systems and access to resources that made the difference between fragility and resilience.

When we accept our own vulnerability just as we accept the vulnerability of others, we can be compassionate with ourselves and with our fears and frailties. (Tutu, 2004:88)

Practitioners in public health services seemed to overlook the consequences of disability on the siblings or other children in the family, despite the growing recognition that the impairment does not only affect the individual but impacts on all family members as well (Coleridge, 1993; Miles, 1995). During the apartheid struggle, black women generally organised to survive, to make ends meet and to challenge their oppression (Meer, 1998). Fortunately the disabled women found the courage to voice needs in an attempt to survive and provide for their families.

### **Sustaining a livelihood: missed opportunities and providers**

Many women in South Africa experienced **missed opportunities** for formal education, as they focused on being activists in the struggle against apartheid (Meer, 1998). Barberton (1998) identified a pervasive sense of powerlessness was the result of resourced-related obstacles to participation. These obstacles are related to poor people's economic circumstances, low levels of schooling and high rates of illiteracy. The consequences for the disabled women were evident in their inability to access information about processes to obtain childcare grants or disability grants, adult education classes and further skills development. There was a subsequent loss of income and food security. Such losses resulted in deprivation of subsistence, understanding and creation. The women's stories provided strong evidence that government efforts to provide education (primary, secondary or tertiary) to children and women, young and old, have yet to materialise at grassroots level. Much of this can be attributed to the apartheid policies of segregation and inferior education for Black people in South Africa. Those policies resulted in huge pockets of poverty and deprivation leading to human poverties, which had very little to do with impairment and more to do with racial discrimination. *Standard Rule 6 on Education* (UN, 1994) emphasises that there should be particular focus on young children and women. The need for skills development and adult education to address the backlog has been addressed through recent policies linked to employment equity by the South African government (Department of Labour, 1998).

Both the literature and the stories in this study show the commonality of experiences with other regarding employment. Fourie *et al.*, (2004) and Taylor and Conradie (1997) found that in South Africa, generally, poverty was the greater factor affecting most black women in South Africa. Gender bias was also found to be significant in the area of work in the Middle East (Abu-Habib, 1997) and Uganda (Mpagi, 2002). Vernon and Swain (2002) refer to studies by Oliver (1991) and Brown (1984) in Britain who found that black

disabled people experience high unemployment rates as well as a concentration in low-paid and low skilled jobs. In a review of twelve years of the *SPEAK* magazine in South Africa, Meer (1998) found that black women were mostly self-employed in the informal sector or in low-paid work such as child care in crèches or domestic work. Barberton *et al.* (1998) and Taylor and Conradie (1997) found the same phenomena amongst both rural and urban women in South Africa. Other significant occupations were vegetable gardening and selling in the informal sector, similar initiatives to the women in this study, which hardly enable a subsistence existence. The small profit that was generated contributed to school fees and buying children's clothes. *Standard Rule 7* on employment (UN, 1994) explores the need for productive and gainful employment of disabled people. It was evident from the women's stories that there is a need to move the focus to strategies that foster sustainable livelihoods, as a first step in order to break the complexity of poverty and disability. Economic development and independence, which would incorporate financial literacy, appeared to be essential skills that were needed to achieve sustainability. The challenge is to achieve this in context of illiteracy and innumeracy. The starting point should be that every one has the means to sustain their family livelihood. From the stories it is evident that this is not happening.

Skills development for self-employment and finding a place to work were identified as synergistic satisfiers of human needs to equalise opportunities, as the human need of identity was met in assuming the provider role; the human need of affection in situations where there was respect and reciprocity in the family and community; the human need of protection through access to health and social services; and the human needs of understanding and creation through learning new skills to satisfy the human need of subsistence. Lastly, a major shortcoming of the *Standard Rules* that emerged was that policymakers and practitioners have not considered the immense deprivations of disabled women in the development and implementation of policies. Nosek *et al.* (2003) mentioned that low economic status translated into poor access to health services in the United States of America. The findings of this study showed that it depended on whether the women received any social security in the form of disability grants. Such access would increase access to training opportunities for skills development through NGOs and DPOs in South Africa (Cockburn, 2003).

### **Health and social services: ignorance and CRWs as a buffer**

Most women interacted with health services as a consequence of their impairment. The interconnections between the barriers to health and social services were evident in the findings: **ignorance** of practitioners and service providers about disability issues had to be addressed through dissemination of information. Mpagi (2002) stressed the important role of government co-ordination and involvement of local NGOs in Uganda, especially in the dissemination of information. The women would then gain increased access to resources and opportunities for development, especially public transport. Hartley *et al.* (2002) indicated the importance of changing professional training so that they play a greater facilitatory role to afford disabled people more opportunities. Hartley *et al.* (2002:74) found that professionals tend to "take over, talk too much, listen too little and know best". Ideally, the interactions with health and social services could provide the best chance of fostering skills and abilities of the women to engage in occupations again, as they resumed familiar roles



and activities through community-based rehabilitation, together with effective referral and support networks (UN, 1994). Being healthy contributes to productivity and well-being. The loss of family support and experiences of ineffective health care created dependency on neighbours for food security in order to meet the human need for protection and subsistence.

In public health services, insufficient understanding of disability issues and poor dissemination of information by practitioners meant that the women experienced difficulty in accessing disability grants. Ironically, inadequate financial resources meant a sense of deep frustration was experienced when trying to access health and social services. The stories indicated that social security in the form of DGs and neighbourhood structures were also identified as synergistic satisfiers of the human needs. However, although women were often the carers, they were not receiving security or payment for this work as stipulated in *Standard Rule 8*. The paradox of DGs is that they have the potential to enable women to assume a provider role and fosters reciprocal support (positive, synergistic satisfier). The moratorium on grant payments happened at a time when the new democratic government was trying to address the inequities in social security grants that had been racially determined prior to 1994. It is incongruous that those who had suffered so much already experienced further hardships and vulnerability as a result of this policy. The current policies in health and social services appear to require maximum correction before a person can get free health care or a DG. It raises the whole issue of compliance and freedom of choice based on having enough information, which is seriously compromised by poverty and illiteracy.

Other writers from diverse contexts have alluded to the notion of women as buffers who absorb the family problems (Doyal, 1998; Goosen and Klugman, 1996; Swartz 2004; Thomas, 2004). Graham (1995 in Read, 2000:53) found that women take continuous and ultimate responsibility for the maintenance of children's health, their recovery from sickness as well as orchestrating social relations within the home and solving problems when these relationships go awry. Graham argues that mothers have to cope with the physical demands and restrictions, as well as feel an ongoing and primary responsibility for the happiness, health and development of their children. The women in this study had to manage the fears and frustrations of other family members and handle their adjustments, which may have resulted in resentment. Thus the boundaries between health, well-being and illness are often quite fragile and the categories of those requiring care or providing assistance become fluid.

In many situations, the **CRWs were a buffer** that offered hope because of their own experience of disability and living in poverty, since they had walked a similar emotional path as the women. The findings provided evidence that confirms training parents of disabled children who were from the same cultural background as CRWs. The CRWs seemed to form a buffer between the women and service providers by meeting their initial need for support, information and access to activities and resources (Haricharan and Rendall-Mkosi, 2002; Lorenzo, 1999a, 1999b; Lorenzo *et al.*, 2003). The CRWs were able to empathise and encourage women to take action and to manage their resources in order to change their circumstances. With time, the women challenged the CRWs, as they felt that they could be potential role-models for the disabled children

in the community. This study has also shown how the CRWs play a complementary role to professionals. Studies in other African countries, Finkelflugel (2004) and Hartley *et al.* (2002) refute concerns of professionals that are related to watering down of skills and service delivery through the training of CRWs. The diversity and flexibility of CBR programmes and workers need to be appreciated. The challenge to health planners and providers is to include disabled women in the management and decision-making of service delivery. Such participation would influence the understanding and dissemination of information about disability issues in a positive and meaningful way. Hartley *et al.* (2002:75) make a profound statement about knowledge:

Knowledge is power... sharing knowledge is progress to a more equitable and sustainable world.

### **Accessing resources: marginalised and potential to be free**

*Standard Rule 5* on accessibility referred specifically to the need for programmes of action to make the physical environment accessible, including public transport, as well as to undertake measures to provide access to information and communication (UN, 1994). While the Standard Rules assume that public transport systems are available and affordable, the stories reveal the opposite, as they are not accessible, attitudinally, financially or structurally. With a few exceptions (Cornielje, 1999; Finkelflugel, 2004; Hartley *et al.*, 2002; Thomas and Thomas, 2002), accessible public transport, information and a basic income have been highlighted as essential resources to equalise opportunities for the development of the women. In reviewing CBR literature, it appears that many projects and programmes have not recognised transport as a major barrier for disabled people to meet together or to participate in different events and opportunities for development and social integration.

The **potential to be free** was seen in the women's expressed need for advice on how to cope with violence and abuse, as the strategies they had tried of reporting or seeking protection from neighbourhood systems for some kind of protection, (such as help from neighbours, reporting to social workers, street committees or family members), appeared ineffective. Thus CRWs provided an alternative means of accessing opportunities and resources. As such, the need for guided action to meet their basic needs was recognised as a potential synergistic satisfier in the absence of a system that offered protection and food security. A predominant trend was that neighbours were friendly, helpful and supportive in survival matters, but struggled to provide effective support to address violence and abuse. If women were able to access information about resources and opportunities, they took the initiative to change their situation. The call for advice is linked closely with *Standard Rule 9*.

The findings reinforced the critical role of local NGOs and DPOs in being an important channel for dissemination of information and access to resources (Finkelflugel, 2004; Kandyomunda *et al.*, 2002). Their role should also facilitate the practitioner's understanding and government's role in CBR, as information impacts on participation (Mirembe and Hartley, 2002). The findings concur with many writers who have proposed that highly trained professionals are best placed as resource people rather than gatekeepers who



control resources (Finkelflugel, 2004; Hartley *et al.* 2002; Lang, 2000; O'Toole and McConkey, 1995; Thomas and Thomas, 2000; Werner, 1995; Wirz, 2000). The women's experiences support the need for an approach, where "the disciplinary boundaries are treated with suspicion in search of a more all-embracing and relevant knowledge of the world" (Baumann and Tester, 2001:7). Such an approach would embrace flexibility and open-mindedness. Baumann is confident that people possess the ability and power to make a world for themselves, as we are agents of our own freedom. Things can be different if we think differently about the world, in which we live, work and die. Support from community services means that the women's desire to develop skills for economic independence should be recognised by all in civil society and especially the health, education, social development and labour sectors in our country. This may go a long way to ensure the right to a better life for all disabled women, as we recognise that ambivalence and uncertainty are the essence of social life (Baumann and Tester, 2001).

In summary, the subtlety and complexity of living with impairment in a disabling society has been uncovered in the findings related to the deprivations (barriers) and potentialities (strategies) of human needs. The stories served to raise awareness about the barriers to human development for women. It is worth highlighting and commendable that even though women recognised the load of poverty in their family was sometimes exacerbated by their impairment, they were able to look for strategies to break the vicious cycle of poverty and disability. The women's pro-activeness is reflected in their commitment to dispel myths of inability and laziness and build up supportive family systems. The women have shown that the vicious cycles of poverty and disability can be broken by the concerted efforts of all stakeholders. Meeting the human needs of the women would equalise opportunities for development, and vice versa. Strategies to equalise opportunities would become satisfiers of human needs so that the vicious cycle of poverty and disability is broken and replaced by a benevolent cycle of humanity and generosity (*Ubuntu*): the collective is stronger than the individual; the individual strengthens the collective.

### PLANNING FOR FURTHER ACTION: SUGGESTIONS

The final step in action-learning involves 'planning' for the next phase of action, so as to continue the cycle towards social change. It is evident that the complexities of disability created tensions for the women as they experienced the transitions from one state of being to another. Read (2000) concurs with Nosek *et.al.* (2003) that women, whether disabled women or mothers of disabled children, are faced with living in a hostile environment. But is this related to the fact that they are poor or disabled, or both? The importance of nurturing emotional resourcefulness was evident, as the women experienced loneliness, dependency, isolation, helplessness, abuse, exploitation, strained relationships and marginalisation. In order to equalise opportunities, disabled women need access to an effective judicial system through street committees, police and access to the courts. This measure appears to be missing from the Standard Rules. Strengthening networks between DPOs and NGOs, as organs of civil society, for collective action to equalise opportunities through creating access to justice needs to be explored.

The stories related to family life revealed the need for more attention to be given to strategies that enable respite and attendant care, which the CRW is in a good position to provide. Women need support to reinforce their strategy of voicing their need for advice and information to overcome abuse and discrimination in the family. Respite should also be provided in the form of social security and income maintenance, so as to facilitate the meeting of subsistence needs without crippling the emotional well-being of women. Social security extended to child maintenance would alleviate the burden carried by single mothers.

Maybe not surprisingly, the area of most difference that creates a major barrier was inaccessible public transport. This barrier affects access to skills development, jobs and other resources. Inaccessible transport means that there is little opportunity to access areas and opportunities where these aspects could be nurtured. The low levels of literacy as a result of poor schooling exacerbated the access to social security and income maintenance and affected job applications and interviews. Culture (*Standard Rule 10*) emerged vibrantly during the NAR workshops, in the women's skills in song, dance and other cultural traditions, which need to be fostered. Their spirituality infused all the workshops through their singing and rituals of prayers. Their symbolism in the creative activities should be explored to reveal the meaning and role of their spirituality in equalising opportunities.

## Chapter 6

# ***This project is very busy:*** **Findings and Discussion**

### Introduction

#### PART 1: Stories of actions: findings

##### **Story 1: *Waiting for transport* – inward change**

*We are also travellers*

*We have to stand up*

##### **Story 2: *Making our voices heard* – outward changes**

Abangane Choir

T-shirts for celebrations

Publication of stories of change

#### PART 2: *No one can say we're disabled now*: discussion

##### **We challenge and change stereotypes**

Our identities are fluid and dynamic

We recognize disability as a penalty or possibility

We manage our responsibilities

We become catalysts

##### **We create a network of action spaces**

We gain confidence through collective action

We learn to listen

##### **Reflective Summary**

#### PART 3: Planning for further action: suggestions



# Waiting to succeed<sup>17</sup>

I am waiting for success in my life,  
whereby God will give me power to succeed in my struggles  
so that one day I can help other people who are struggling  
and teach them that they must take what they have,  
even if it's small,  
and know that success lies within themselves.  
I am waiting for success in my heart;  
As a disabled person, even if I'm sitting,  
I have hope inside.



I am waiting for success in my problems;  
Since I became disabled, things are slow,  
now I must first think  
about how I'm going to get something,  
then wait until I get it...  
I am waiting for God  
to give me freedom  
to get a job, to get money  
so that I can buy small things to sell...  
so that I can have a perm  
and be beautiful more than this.



I am waiting for happiness,  
for hope that God will add more years to my life...  
I am waiting to be helped with my disability,  
for a walking stick to help me walk,  
because my legs are too lame to walk on my own...  
Some hardships in this world come and go.  
I am waiting for Jesus to come and free me  
from my ties and problems.  
The devil is waiting for big things from me  
but he will never get them  
because I don't belong to him.  
I pray and worship the One above who helps me.

I am waiting to succeed  
in all that I wish and hope and pray for.  
And I will see the results of all these things  
in my disability and in my children.

<sup>17</sup>From a creative activity with women in a NAR workshop, 11 May 2000. Published in Lorenzo *et al.* (2002). The poem is an edited extract from a published collection of their stories about living with a disability in Khayelitsha.

## Chapter 6

# ***This project is very busy:*** **Findings and Discussion**

### INTRODUCTION

Chapter Six consists of three parts (see Figure 9). Part One began with a composite poem of the women from a NAR workshop. The poem portrayed some of the tensions of personal and social change, which they had to negotiate in pursuit of freedom, inclusion and equal participation: disability and innate potential, realism and anticipation, fact and faith, permanence and transience are juxtaposed throughout the poem. The rest of Part One focuses on exemplary stories of actions by the women to equalise opportunities for their development at multiple levels. Story 1 presents the exploration of experiences of accessing public transport during the course of the study. Story 2 describes the Arts and Culture cluster one of the six skills development clusters that the women participated in over a period of six months. I have selected this cluster, as the women's actions address the complexity of equalising opportunities for disabled women in contexts of poverty and disability discrimination. They highlight essential lessons related to strategies for change.

Part Two presents a discussion on the interpretations of the actions, supported with relevant literature, which contribute towards building of my thesis. The chapter concludes with Part 3 related to suggestions for planning further actions.



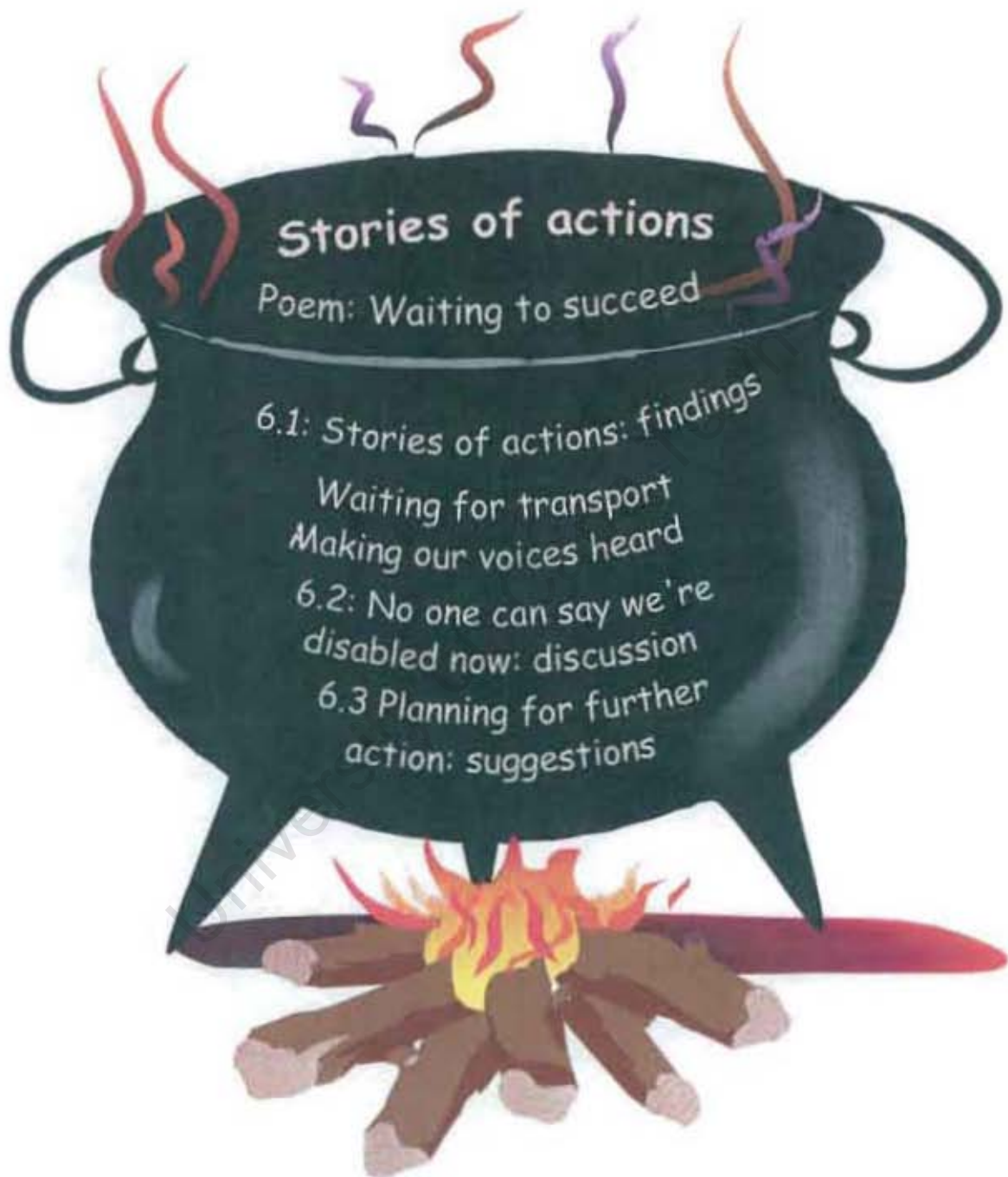


Figure 9.  
Stories of actions

## STORIES OF ACTIONS: FINDINGS

The first part of Chapter Six focuses on the two action stories. The first action story, *“Waiting for transport”* explores the inward experiences of women’s attempts to access public transport. The second action story: *“Making our voices heard”* describes three of the five action-learning groups in the Arts and Culture cluster that reflect the outward changes that the women experienced. Thematic analysis of the transcripts from the storytelling and NAR workshops, and field notes from over the period of the study using the reflective stance approach (Meulenberg-Buskens, 1999) provided a longitudinal perspective of the changes that the women experienced across the lifespan of the project. Thick descriptive data was selected to represent the women’s experiences in context. Some of the quotes represent dialogues composed from across workshops. The two action stories suggest that the inclusion of the women into local development initiatives was feasible, as they developed strategies to tackle the inward and outward barriers to their development.

### *Story 1: Waiting for transport – inward changes*

#### Introduction

Public transport was recognised as a critical barrier early in the study. A significant number of women sustained their impairment as a result of a road traffic accident or using public transport such as buses or taxis. Paradoxically, public transport also posed a major barrier to their development, as it is often inaccessible structurally, financially as well as attitudinally on the part of the drivers and other passengers (see Chapter Five, Cycle 3). Accessible public transport is an issue that has an impact on many aspects related to the equalisation of opportunities for development and social integration in areas such as health, rehabilitation, education, employment, social security, culture, family life and religion. One workshop early on in the study focused on the experiences of accessing public transport. The Western Cape provincial chairperson of DPSA, who has been a member of the National Environmental Accessibility Project, presented a critical incident story to the women on the travel chain and their rights to accessible public transport as citizens. The action story presented here describes how the women recognised the inward barriers to gaining access to the public transport system, which mobilised them to take action collectively. The action story reflects the complexity related to the nature of public transport barriers and possible solutions experienced by groups in poverty-stricken contexts.

#### *Transport systems in townships such as Khayelitsha and Brown’s Farm*

It has been estimated that more than 80% of the people in Khayelitsha use public transport for travel purposes in the form of rail, taxis, buses and least of all private vehicles (Dyantyi and Frater, 2004). The inconvenience that is incurred by the commuters is more significant. Long travel distances, high costs and overcrowding coupled



with long commuting times and a general lack of personal safety characterises an inefficient public transport sub-systems in Cape Town. Low population density in certain areas makes access to public transport difficult, expensive and unsafe. Taxi operators are members of Codeta, a predominantly Khayelitsha-based taxi association. The way the public taxi system works in the townships is that passengers have to wait for the taxi to fill up (legal capacity is a maximum of sixteen people) before it will depart from the taxi rank. Therefore, a passenger can wait for up to an hour or more on some occasions. Passengers are also dropped at a taxi rank and not door-to-door. Until recently, if people in Khayelitsha wanted to do bulk buying of food, they would have to travel outside of Khayelitsha for access to significant chain discount stores. As Dyantyi and Frater (2004) noted the implications of this for incidental and weekly earners with little income security are significant in terms of time and money spent on transport. Shopping patterns are typified by frequent small purchases, particularly of staple and perishable foodstuffs from spaza shops or convenience stores within walking distance of their homes. Cost margins are often as high as 25% above the wholesale price.

People from impoverished communities have struggled to gain daily access to economic and social resources because of long distances, the lack of transport facilities and an overall poor level of service. Work opportunities are not close to where the majority of poor people stay, thus increasing the financial burden of travel that they carry. Few people are fortunate to own private vehicle. Those who are fortunate to have a private vehicle offer a service at a cost higher than public taxis. In some situations, families have no option but to pay for the convenience and accessibility of private transport, especially in times of illness or emergencies.

The Dial-A-Ride Project was initiated as a pilot project of the Department of Transport in 1999 and 2000 as a result of lobbying from the Disability Rights Movement. It provided a limited accessible mini-bus service for disabled people who have difficulty in using existing public transport. Individuals were assessed for their mobility and ability to use public transport. If they were registered as a user, they had to phone in and book the service each time they needed it. Disabled People South Africa continues to campaign for accessible public transport as a strategy to equalise opportunities for development.

### **The women's experiences**

Public transport was identified as an essential resource for promoting skills development for sustainability (Lorenzo, 2004). Public transport accessibility and the distances women had to travel to participate in different events or opportunities for development was linked closely to the planning and organisational capacity of the women and the organisations who worked with them. Unavailability of money was another barrier to transport, which made effective planning and organizational development difficult for the women. These factors were key issues that impacted on the sustainability of different initiatives.

The action story explores experiences of the women captured in the theme “*Waiting for transport*”, which illustrates the inward reflection that occurred as the facilitators explored the nature of the problem with the women. The sub-themes and categories that enrich the theme are reflected in Table 8, which will be discussed in-depth.

**Table 8: Factors influencing accessible public transport for disabled women**

THEME	SUB-THEME	CATEGORY
<i>Waiting for transport.</i>	<i>We are also travelers.</i>	<ul style="list-style-type: none"> <li>• Poor Planning and organising</li> <li>• Time spent waiting</li> <li>• Taxi violence</li> <li>• Emotional vulnerability</li> </ul>
	<i>We have to stand up.</i>	<ul style="list-style-type: none"> <li>• Negotiating collective responsibility</li> <li>• Beginning to mobilise</li> </ul>

#### *We are also travellers*

It became evident that there were tensions between the women, the CRWs and the co-ordinators related to **poor planning and organising** about who was responsible for the organisation of transport for participants of the research workshops. The analysis of data identified poor communication and time management as factors that compromised effective planning and organisation. The women felt that they did not receive information about the workshops in time. Even though the workshop dates were planned at the beginning of the year (i.e. the second Thursday of every month), it appeared that there were expectations that there would be reminders. The women and CRW co-ordinator raised these difficulties, as seen in the dialogue, which sought to challenge the perceived passivity and dependency on NGOs for transport:



**Women need access to public transport to market their produce**

Woman: *Transport is a problem. Listen to me carefully. The CRWs come at this moment to tell you that there is a workshop instead of telling you a day before. You are waiting for transport, you are waiting for transport that won't come, especially transport from our home.*

MJ: *Which one is that?*

*Woman: SACLA's transport. I phoned and they said the driver was not there and the co-ordinator was not there as well. They didn't know what's happening with the transport. So we have a problem. We need to look at these things from different directions.*

*CRW co-ordinator: I have a request, I'm struggling ...at this moment and minute, I would like women to volunteer and say 'I can help you with organising the women's group'.*

*MJ: From CRWs?*

*CRW co-ordinator: Even if it's the women...*

*CRW: I was going to explain about participants hearing late about the workshops. We went to Makasar first but they didn't know where people had gone. So that is why the women don't hear about the venue.*

*MJ: So if CRWs don't hear about the venue it's worse for the women. So that is why [the CRW co-ordinator] is saying she needs people to help even if you swop and that gives you the skills and you just ask her how to do it. (July, 2000)*

Through such dialogues, the women learnt the importance of planning and organising transport as an essential skill to accessing resources and opportunities. It was agreed that the co-ordinators and CRWs would tell the women about the venue early, but women also had to take responsibility and diarise the dates themselves. Thus the relevance of planning and organisational skills linked to accessing public transport was recognised, as essential for sustainability as it would ensure access to resources, opportunities and markets for their produce. Both of these aspects were influenced by access to and availability of public transport.

**Time spent waiting** for public transport was a common experience that the women related in their accounts of actions taken. At one workshop, Gubela shared that she had gone shopping for the ingredients and equipment for catering group with the research assistant as had been planned in the previous workshop. Her experience reflected how time consuming it was to rely on public transport.



**Women learning to make chocolate**

*We got the equipment and ingredients. When I came back, the members who I said should wait were gone because I was late due to transport. They gave up that day and they don't finish it by going home before time. I was burnt by the sun because we didn't get chocolates from the first place. We had to go to town. I sat there waiting for transport and I gave up and went to the bus. But with the group members it was so difficult to wait in the house. Later three women from U area arrived. We made chocolates at my place and the group members took chocolates worth R45 to sell. We have not met again with them. I made R18. We were going to sell in town but the chocolates were sold before then. They sold easily. People want them even now. (Gubela, July 2000)*



In contexts of poverty, it was suggested that it may be more feasible for groups to meet together once a week instead of every day because of distance and transport costs. Women wasted an enormous amount of time waiting for public transport. Such time seemed sufficient for planning, organising and decision-making to maintain momentum of the group. In between, the women would go about their work individually but still pool their resources.

The situation of public transport accessibility was complicated by **taxi violence**, as illustrated in the dialogue between Marjorie and the women from the one area, who were disillusioned with Dial-A-Ride as well:

*Bongiwe: There is also this taxi violence and we are scared to come nearer them. You hear these bullets whilst you are still at the taxi. Sometimes [the taxis] leave without even closing the doors.*

*Group: We had Dial-A-Ride but drivers are scared of entering the communities now because of taxi drivers fighting. We are struggling with transport now.*

*MJ: We won't expect you to come out of your houses when there is a fight. So we won't meet. We are talking about solving the transport problem at normal times. (July, 2000)*

Exploring the feasibility of using public transport beyond just the PAR study reflected the complexity of accessibility issues. Besides the structural, attitudinal and financial factors described earlier, **emotional vulnerability** was identified as a further factor that influenced the women's confidence in accessing public transport. The women had to find the courage to challenge unacceptable behaviour of service providers and take responsibility for their own well-being. A dialogue occurred trying to find solutions around using public transport, as well as to establish mutual accountability:

*MJ: So it lies with us, what are we going to do? You need to phone Dial-A-Ride. So you'll be able to say to Dial-A-Ride if he comes at 11h00 "You have been asked to be here at 10h00, why are you coming this time"? If you are not asking them because they were late when you went to town, that is not Dial-A-Ride's problem. Then you will need to be early so that you tell them, 'We are watching you; you've been coming late all the time'.*

*Woman: MJ organised Dial-A-Ride for us, but we got to town at 17h30. They were booked and they agreed. I went to town in my old apron. When I asked the driver, "Where have you been?", he said the vehicle was broken, but he had a strong smell of alcohol. Dial-A-Ride doesn't improve.*

*MJ: So for the women's group, is there a person who used Dial-A-Ride? For example, in your area you say, "there are four of us and I'm going to use it".*

*Woman: The reason why we didn't bother about transport is because we had good transport [contracted by SACLA] except the time problem. The drivers have care, not this thing of being dished out. It's like the drivers have been trained for this.*

MJ: *But if you are not treating him nicely, you won't see his good side if he has to come back and forth to your group.*

Woman: *The problem is still with us.*

CRW co-ordinator [to TL]: *It seems as if when the drama group asks for money for transport they have committed a crime. Were you waiting for the women to fail first and then you would show them how stupid they are?* (July, 2000)

The dialogue illustrated how the women's vulnerability influenced their decision-making regarding their preferred form of transport. Emotional vulnerability was also seen in perceptions that only some groups got money to cover transport costs, which left other groups feeling angry, frustrated and further disadvantaged. There was a need to build self-esteem and trust to overcome suspicion. Such interactions indicated the value of building emotional resources and capacity to understand how organisational systems work so as to build sustainability in accessing resources. An action-learning approach allowed the facilitators the space to deal with such events as they arose.

### *We have to stand up*

On two occasions only about fifteen women attended the workshops, only to discover later that many of them seemed to be left waiting at their 'stations'<sup>18</sup>. Thus **negotiating collective responsibility** was necessary because of the barriers in public transport described previously. Through dialogue and critical reflection with the women on the reality of the situation, some of the group began to realise that their endeavours of business development depended on negotiating collective responsibility to ensure accessible transport:

MJ: *The problem with transport, we know SACLA's contract driver is on his own and there is a big group. What time must he start if he is going to take so many people? Are there people who are ready at 7h00?*

Group: *No.*

MJ: *So we are causing problems for him. If we say he must start at 9h00 we end up rushing because we don't have enough time. There is one transport and you want him to start at 9h00. Is that not a problem?*

Group: *It's a problem.*

MJ: *What must we do?*

Group: *He must start at 7h00, [some women said at 8h00].*

MJ: *Even if he starts at 8h00 people are not ready and he has to go back to them. He goes twice to the people.*

Group: *The problem is there are many groups.*

Group: *We must wake up early if we are going for the workshop. Waking up early one day in a month is nothing. It's better because the transport will fetch you at home. How much more difficult if you were rushing for another transport?*

Woman: *There is nothing as important as being punctual. We are the cause of the problem. If the*

<sup>18</sup> Pick up points organised by the CRWs in each area where the women assembled to be picked up at an agreed time.

*transport comes and it leaves we mustn't complain.*

*MJ: So let's say the transport mustn't come back. If I'm not ready they must go.*

*Group: Yes, it must leave you. (July, 2000)*

The women realised that they had to negotiate collective responsibility for organising transport for monthly workshops with the CRWs. This meant that by the first Friday of the month the CRW co-ordinator had to tell CRWs of any changes in their staff meeting, so that the CRWs had ample time to disseminate the information.

As women took more collective responsibility, there were renewed signs of **beginning to mobilise** around accessing public transport. The research assistant created a storytelling 'code' (Hope and Timmel, 1995) related to how disabled youth in Eastern Cape addressed the barriers to transport. The code triggered a lively discussion on forming a committee to go and see the mayor in Khayelitsha, and reviving the committee of Masiphatisane Disability Forum. The research facilitators challenged the women, some of whom were committee members of Masiphatisane Disability Forum, to 'wake up'. They questioned the women about why they left it to a disabled man to go alone to see local councillors. A CRW supported the idea of women choosing their own committee:

*CRW: Things start happening when women get up but if we wait for men 'Oh no'. It seems as if we have to stand up because really there will be development.*

*Bulelwa: As women, we are the ones who always have a need to travel and men don't. If we say we'll wait for them, there will be no development, the way these taxis are shouting at us. The drivers (mainly male) don't even mind if they need one more person in the taxi. If I'm standing there they would rather go with a taxi that's not full and I must take the next taxi. (July, 2000)*

There was a sign of growing interdependence amongst the women as they problem-solved together. A committee was elected. The women also decided to organise transport for the monthly workshops as a small group in each area where they stayed, rather than relying on SACLA to provide the transport for everyone. The latter system had delayed the start of workshops. SACLA would organise transport for the few women who were not able to use public transport because of more severe mobility impairments. The situation of the young women with intellectual impairments was discussed to ascertain the safety of them using public transport. The suggestion was made that women travel together rather than on their own.

A system of payment of taxis together with the risk of creating dependency on the NGOs or the core planning team was discussed. Women were borrowing money from a neighbour or a CRW with the expectation of being reimbursed by one of the partner organisations in the research. There was a need to address the pattern and assumption that the NGO would provide transport. It was seen, rather, as a matter of how the women budgeted and planned for activities. There was a suggestion that the group use research money as seed money to generate money – each participant would be given R5 to make something and from



the profits of selling they could pay for transport. There was also the need for better communication, to look at different ways to overcome barriers collectively.

In summary, the action story on public transport showed how central accessibility issues are to the empowerment and inclusion of women. The current public transport system is fraught with barriers to participation, such as taxi violence and the abusive behaviour of drivers, which left women feeling emotionally vulnerable. These barriers are particularly problematic for the women, as it hampers their efforts of accessing opportunities and resources. The distances between the areas where women stay made it difficult for practitioners and members to communicate changes in what was planned and in meeting regularly as there were limited phones and transport. Action-learning enabled the women to gain confidence in decision-making as they explored choices and options for action. The women gained a sense of being in control of their destinies. They began to use collective problem solving as a strategy to mobilise for accessible public transport. The location and distance of resources, opportunities and markets necessitated confidence in planning and organisational skills. Through the narrative action-reflection workshops the women began to effect change as seen in the sub-theme *'We have to stand'*. The action story revealed the tensions and dynamics of moving from dependence and blaming to taking responsibility and self-empowerment. These tensions have to be balanced to enable and sustain change.

### Story 2: *Making Our Voices Heard* – outward changes

The NAR workshops provided opportunities over a six-month period (June- November) to identify and organise women into six skills development clusters. The second story reflects the innovative ideas that grew out of the NAR workshops, and the collaboration between the three partner organisations, SACLA, DPSA, and UCT. The main plot *"Making our voices heard"* runs throughout the three action-learning groups to show a collective sense of action, which grew out of their understanding of creativity as a strategy to equalise opportunities. It was clear from the longitudinal analysis of workshop transcripts and field notes using the reflective stance approach (Meulenberg-Buskens, 1999) that there was an abundance and diversity of skills amongst the women, irrespective of the nature of their impairment (appendix 10 for an outline of the different clusters). The women's strategies were not necessarily being used to their full potential to meet their fundamental human needs.



Women engage in drama training

This action story describes three of five action-learning groups in the Arts and Culture cluster. The cluster was chosen as it demonstrates an innovative contribution to disability awareness and advocacy while at the same time as showing potential for entrepreneurship, namely, 'Abangane Choir'; 'T-shirts for celebration of public holidays strategy'; 'Publication of stories'. The action-learning groups about 'Drama training and community workshops' and 'Media training' can be found in appendix 11. Some women participated in more than one of the action-learning groups. The data for the Abangane<sup>19</sup> group was derived from participant observation and consultative dialogue groups, as there was a technical problem in videoing this workshop. The learning groups are presented as narrative format, with supporting data from the workshops.

### **Action-learning group 1: Abangane Choir**

*We are planning that all of us, as disabled women, become part of a choir...we wish to get a person who knows drama and music to help us. We are going to practise to be good.* (Small group, June 2000)

From observations of what happened at the beginning and end of each NAR workshop, the research facilitators reflected back to the women the strength of their singing and dancing skills. The women decided to form a choir that would enable them to combine their cultural skills with raising awareness on disability issues and advocacy to challenge stereotypes related to disability. The women and CRWs performed



**Abangane Choir performing at a community event**

at various community events and celebrations such as weddings, birthdays, and funerals. They began to take advantage of public events where they could market their skills as well as develop links to disability awareness and advocacy e.g. SACLA's 20<sup>th</sup> Anniversary celebrations.

The development of the choir provided the women with an opportunity to meet many of their human needs (Max-Neef, 1991) such as identity, creation, affection and participation, as they made the decisions about how to develop the choir's potential. They learnt how to resolve conflict related to membership and the functions that the choir would participate in, as well as build group relationships. One such incident occurred when one woman shared her feelings of dissatisfaction of how decisions were made regarding membership.

<sup>19</sup> A Zulu word for friends.





**We create a network of action spaces**

There was a request by another member for the women to be flexible and adapt to the situations they were in at that moment. She reminded the group that in Abangane they valued the principles of openness and trust to operate and understand each other well. There was no intention to exclude people but distance between group members made communication difficult. This openness touched the first woman who got up and hugged those with whom she had quarrelled.

The challenge of building group cohesion was difficult as some members attended sporadically, because they were involved in other activities. The group also experienced difficulties in accessing resources needed to plan attitude-changing strategies. The women reported that they were too far from each other and didn't have telephones to

communicate any changes to plans. The group also struggled with costs of transport to get to practices, which happened twice a week. Thus there was a need to find focus to ensure commitment and accountability. They decided to have a constitution to guide membership. The members recognised the need for management and organisational development skills to build capacity to address the difficulties of working in a context of poverty.

### ***Action-learning group 2: T-shirts for celebrations***

PAR exposed the women to opportunities for further skills development, linked to national public holidays such as Youth Day on June 16<sup>th</sup> and National Women's Day on 9<sup>th</sup> August. The women were involved in designing a t-shirt with messages about disability to their families and the community that they brainstormed in order to challenge stereotypes and raise awareness about their abilities and desires (appendix 12). Together with the symbols of identity from the stories women had told earlier, we designed a t-shirt with the assistance of a disabled graphic artist, which was sold during the celebrations of National Women's Day in August 2000 (see Figure 10 for design and appendix 13). Using t-shirts to make their voices heard on disability was a success, as the t-shirts were an accepted part of relaying the messages of liberation in the mass liberation movement, in organisations such as African National Congress (ANC), the Congress of South African Trade Unions (COSATU), and the South African Democratic Teachers Union (SADTU).

The community responses suggested that the t-shirts were a strong advocacy tool, as well as a way of disseminating the results of research in the community. The potential for engaging the women in advocacy and awareness-raising using the medium of t-shirts seemed to be non-threatening and built their confidence, as family members and the community took an active interest in their experiences. People in the community engaged with the women when they wore the t-shirts and asked questions. Thus it was found to be more



**The facilitators and the women designing the T-shirts**

effective in translating findings in this context where there were low literacy levels, as it engaged people in conversation with the women probably more than the usual means of journal articles or research reports. The t-shirts encouraged interaction and dialogue, which helped to demystify the research process and actively engaged the women in sharing their experiences of the research. One person even said this [t-shirt] is teaching us a lot about you disabled people.

*I wear it ... to the big SANCO<sup>20</sup> meetings and would sit to see whether they would give me a position. They would talk and at the end ask me if I want to say something. I would see that t-shirt forces them [to talk]. (Bulalwa, Nov 2000)*

Evidence of the impact of the t-shirts was illustrated in how the community responded to the t-shirts, which the women shared in a NAR workshop a few months after the t-shirts were sold:

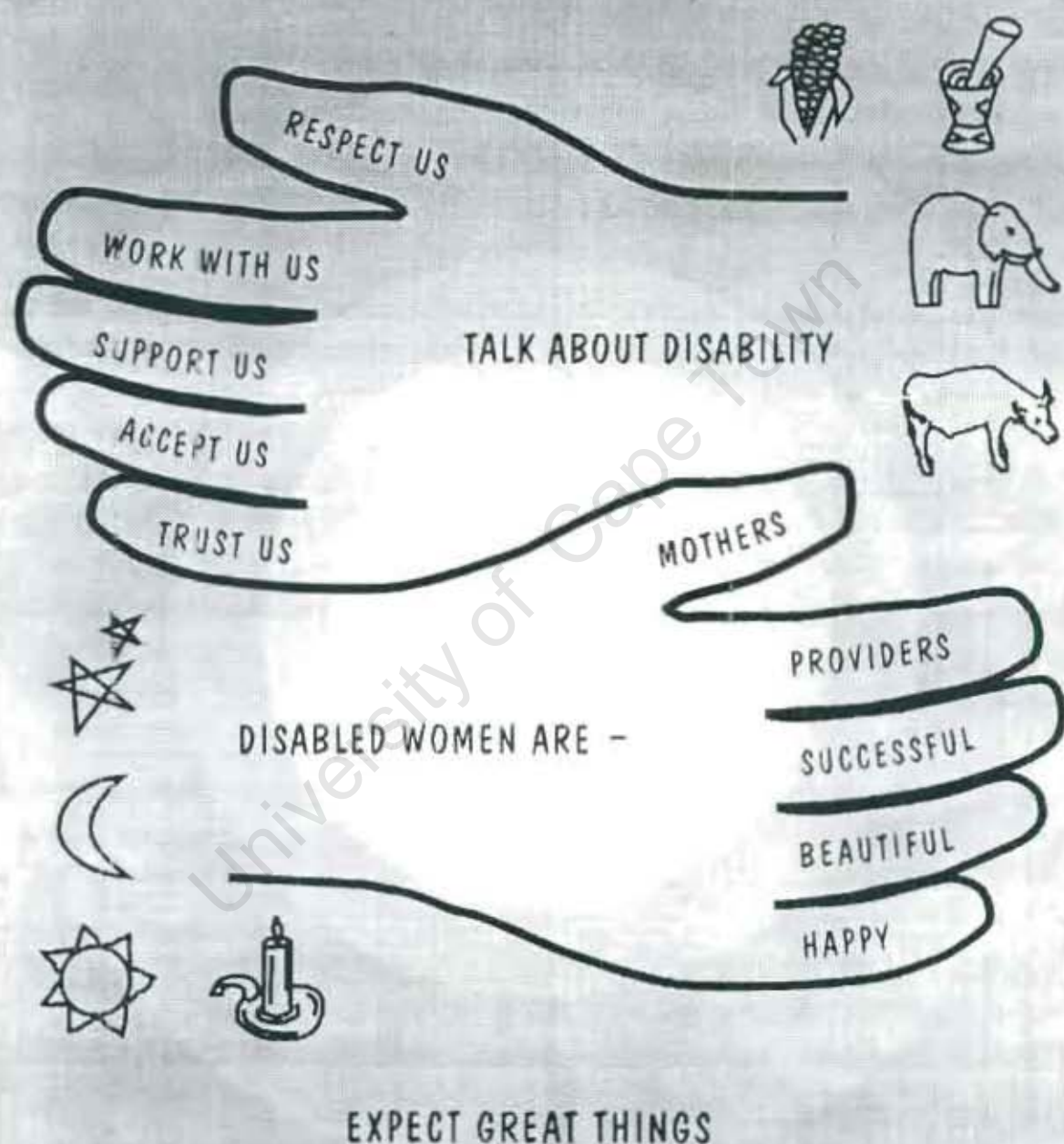
*There are three people who have stopped me in [City centre] and read everything even from the back... Our children liked them as well.  
I didn't know that what we were saying here [in workshops] could be written down on a t-shirt and have people reading it.  
Even scholars usually stop me to ask who is selling the t-shirts.  
The CRWs from a rural area were even asking if they could sell them to men because they want them.*

The sale of the t-shirts was also an income generation opportunity, as the money that was made from selling the t-shirts went to the group. There is the potential for t-shirts and similar strategies to be used more aggressively in the Disabled Women's Development programme of DPSA as a means of advocacy. Organisation such as the Treatment Action Campaign (TAC), a national advocacy campaign for HIV/AIDS treatment, has done this very effectively by engaging in the wider public in identifying with the situation of people who are HIV positive, by selling t-shirts boldly emblazoned with HIV positive to the wider public.

<sup>20</sup> South African National Civic Organisation



# DISABLED WOMEN ARE PROUD AND PASSIONATE



An Action Research Project of UCT • DPSA • SACLA  
Funded by MRC & Women-in-Research (NRF)

Figure 10 T-shirt: design

### Action-learning group 3: Publication of stories of change

Fifteen women who had participated regularly had their stories about the changes that happened for them published in book titled *On the Road of Hope: Stories of Disabled Women in Khayelitsha* (Lorenzo et al., 2002)<sup>21</sup>. It was launched on National Women's Day in August 2002. The women were excited and proud when receiving copies of the book, which raised their morale and self-esteem. The women also performed a drama at the Festival. Profits from the book have gone back into the Disabled Women's Development Project of DPSA for other development initiatives.

Bulelwa's story presented here represents the changes experienced by the women through participation in narrative action-reflection workshops. I have chosen Bulelwa's story as one of the women who participated regularly during the period of the study. The story represents most vividly the common trends in changes experienced by other women. The changes were identified using the reflective stance approach (Muelenberg-Buskens, 1999) (see Chapter Three). The earlier part of Bulelwa's story was introduced in Cycle 1 of Chapter Five. Marjorie's story was chosen as she was disabled herself, and it reflects the changes from the perspective of the research facilitators. The narrator's voice gives a character sketch on each woman at the beginning of her story in regular font and highlights the critical dimensions of change at the end of the story. The voices of the women and facilitator are in italics.

#### **Bulelwa: A better life together**

Bulelwa became the 'disability evangelist' in the study. She was a vibrant entrepreneur, very hard-working while at the same time as being very concerned for the well-being and growth of the women. It was significant that the women began to recognise changes in each other over a period of time.

*After the first workshop where I told my story, I felt much stronger. I realised these workshops could really help other women in the same situation as me. Our rehabilitation did not help us return and settle back with our families or communities. Here I made a clay sculpture of a plate and two women to share how I changed from gaining knowledge of disability rights and advocacy skills. The workshops helped us to find knowledge and information for each other. We felt happier. We recognised the gains we've made in changing our living conditions. These skills have led to a better life together. I made myself using clay. I want to show you that before I became disabled, my body was thin. I was small before and you can now see how big I am. So I want to share the good news so that others can be big like me. I must be the light, even in the community and preach about disability and how they can treat disabled people. I talk about disability, I became more confident and gained skills in being able to change things. I was used to speaking in church and sharing my testimony. Now I speak about disability. I also loved to sing and dance.*

<sup>21</sup> The book was sponsored by the Centre for the Book and formed part of the Adult Literacy Week in September 2002.



*I see myself as a light for other disabled people and I'm not afraid. I know I'm able to talk. I'm usually shy, but since I've been here I am free. I used to worry a lot at home, but since I've been here I'm much better. When I see my neighbours quarrelling, I say to them, 'Call your family and sort this out'. Later they say to me, 'Really we called them and we solved it'. So that is why I'm saying I'm a lamp. I see that even with the women, there is change. I'm able to see how they were before and how they are now. Ever since they have been meeting in the groups, the load was taken away and everything has been lighter.*

*So I was not the only one who wanted to shine as a light to change attitudes to disability in ourselves, amongst our families and our neighbours. The workshops also helped us see how we could heal each other. The workshops gave us courage to be visible in our families and community again. I told a story from the Bible: 'I identify myself with the person who was next to the dam and people were coming and going not helping him. So Jesus asked him, 'Do you want to be well?' 'I want to, but I don't have a person who will help me and put me in this dam'. Jesus said, 'Take your mat and go and by those words you are healed'. So now I'm well, but it's sad when you see others having problems.*

*Thandiswa told us how much she had been helped: "I experienced deep changes about how I feel. I used to cry a lot, but since I met other women, I got new ideas. I joined the Nobantu group<sup>22</sup>. When Bulelwa introduced me to the group, I was happy and I became one of them. I understand more about this impairment now. When I became disabled, I always undermined myself when I was with my friends. I always sat in one place. But when I met with the other women I became stronger and that thing of always feeling sorry for myself is gone. My in-laws did not love me but today my house is always full. I'm strong. Today I'm not crying. Now no one can believe that I used crutches before. No one can say I'm disabled now, I identify myself with the sun because before it was dark and I didn't want to accept my disability. I couldn't even sit in the sun. Now I can do things with my hands and I got a certificate. After that I could do things for myself. Now I'm like a mother in the house even when the children are not there. I never used to be like that. I used to wait for them to come back from school. Now I feel that I can do anything."*

*Another woman told how her children had found support from the workshops as well as they also felt the pressure to change the stigma of disability. Gloria said: "I'm receiving a lot of support from my family. My two children always show interest in what I'm doing. At school they used to be laughed at by other children because of my disability. But they told them that with their mother, they can't see any disability, but they see a mother who is a role-model and who can afford everything unlike other mothers who can't afford the basics. You see other mothers who can't even afford buying their children shoes. As mothers we learnt to teach our children respect and good social skills". Gloria also challenged us: "Your child has a right to ask for things from you, but you need to teach them to talk*

<sup>22</sup> A small business group that was initiated in Site C, Khayelitsha in 1996 that started with some of the disabled men with the support of the community rehabilitation workers.

*nicely when they are asking for something. They mustn't go and ask for something from other people because they think you can't do things since you are disabled."*

*However, some other women still experienced strain with family members. As a group, we learnt how to respond to these feelings of struggle and problems that others still experienced. One woman cried as she spoke about how her mother still expected her to meet the financial needs with her DG: "I got sick and tired of my mother because whenever I phone her, she always nags me and asks me for money. 'Do you have R100 that you can bring me when you come to visit me?'. I don't visit her and I'm not going to visit her anymore. I made that decision and I'm sick and tired of this whole thing."*

*Many women spoke at once: "But it is your duty to phone her. She is your mother and she will always be your mother, so you need to talk with her".*

*Then MJ told us: "We hear you, sis, and I think we must listen to her and things are going to change as time goes on".*

*We found that the workshops were a good space where we felt well looked after. One woman made a clay sculpture of a tree to symbolise the potential amongst us. The tree's roots represented the women growing as different people from different areas. We've made friends as we have been together in the workshops.*

The passion and energy for advocacy and spreading the message revealed an evangelical zeal. Bulclwa grew in confidence to speak about disability to other women as well as the wider community organisations. It inspired her self-development. She mobilised the women to re-think their images of disability and challenge public stereotypes. They acted collectively to raise awareness and advocate for change in attitudes towards disability.

### **Majorie: Now I listen very well**

This story reflects the changes that Marjorie experienced as a research facilitator.

*As a disabled woman, I was very surprised and at the same time proud of being asked to be part of this participatory action research study with disabled women in Khayelitsha and Brown's Farm. We know that we as disabled people are always being researched. We just accept things brought to us by other people. But this time it was the women ourselves who contributed to the whole process. We are the ones who showed what we wanted from the research.*

*When we started the study with storytelling workshops, there were many women who were crying, who had nobody to talk to, nobody to cry with. But when we met once a month on our days, we talked about our stories, we talked about our pains, we talked about our joys. That made me gain as a disabled person. I realised that as a disabled woman I can listen. Maybe I didn't listen too much to disabled people before, but now I listen very well because I know their joys and pain. Sometimes a woman will withdraw because she doesn't want to say something, maybe especially to new people. When I say to her: "I've been there, I know what you're talking about, so come out with it even if it's going to hurt you", then that person opens*

*up and talks about what has happened. The women also knew where I'm from as I used to be in the same position as them – looking for work as I had a family to support. I'm on a wheelchair.*

*So now we are like sisters. We are not afraid to talk to one another about our problems. We are not afraid to talk about our pain. When we come together we come to share. We started by sharing our stories, whether they were bad, whether they were good. We cried for each other, we cried with each other. At the same time we made it possible for each person to heal from whatever they had suffered. When we first talked with the women we saw that although we were all disabled, we were also different.*

*As a facilitator the other women saw someone who is disabled and who at the same time was capable of sharing with them and of knowing what we should do together. We have gained a lot from each other. I gained strength from them; I gained just from sitting down with them, even if we were just talking. We found a woman who was in a different position when she first came in, in a different state. But today we are talking to someone else who is so grown. Often the woman herself doesn't even realise it, but we saw how she came in, and the difference today. Women are also taking their businesses very seriously. Those who are starting small businesses have gained. They came in not knowing what they were going to do with their hands. Many had been sitting at home not knowing what to do. But today they are proud of what they are doing, having skills of many kinds. Some of the women are now working in the shops.*

*I can be proud to say the project that we started is going to come to fruition. We are still continuing and there are still many, many women that are joining because they have heard what the others are gaining. I've learnt that research is not a one-day or one-month event. It is a stretch. We went a long way before we got what we wanted. We are saying that if we can do this again, we will do it with others. There are so many women out there whom we would like to touch. Other researchers must include the disabled people as fellow facilitators of research. Disabled people must not be 'the researched'. We want to tell the researchers what we expect from them. The research was something that said: "Let's go forward, there's me in a wheelchair who's already there, let's follow, maybe we will reach where she is today".*

Towards the end of this research, Marjorie was elected to represent the ANC as a uni-city councillor. It meant that her involvement in the group decreased because of time constraints, but she remained in contact with the women. She mentioned that she felt confident to stand for election as a result of the research.

In summary, Part One of Chapter Six has described the actions and changes experienced by the women who participated in NAR workshops, as part of the PAR study. They demonstrated strategies to remove barriers to inaccessible public transport, as well as making their voices heard. The changes were communicated through various mediums, which indicates entrepreneurial potential in the group is alive and well.

The two action stories suggested that there was not much about these stories that would distinguish the women from other women. Such evidence supported the fact that their impairments did not make them unable to learn and achieve. The action stories on accessible public transport systems, advocacy and the potential for tourism entrepreneurship would be applicable to other disadvantaged groups as well. Critical lessons that can be drawn from these two action stories are discussed in the second part of Chapter Six.

University of Cape Town

## Part 2

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### *NO ONE CAN SAY WE ARE DISABLED NOW: DISCUSSION*

It is important to believe that change can happen. (Coleridge, 1993:86)

The women's stories of actions and changes in the previous cycle bear testimony to Coleridge's affirmation above. Their stories shed a new light on the ordinary, everyday activities of the women in the home and informal trading sector, how they balanced and juggled these responsibilities while getting little respite from the daily grind and struggle against poverty. Self and group reflection on action helped to build momentum for change amongst the women who participated in the study over a period of two and a half years. There were meaningful outcomes and important lessons learnt.

In this second part of Chapter Six, insights gained about how the women equalised opportunities for their development that emerged from their new understanding of identity are described. Combined with the social model of disability, the synergy between equalising opportunities for meeting human needs helped the women and research facilitators understand the complexity of poverty and disability. The findings suggest that the inclusion of the women into mainstream development initiatives is feasible, if stakeholders appreciate differences and build on commonalities. The interaction between the strategies to remove barriers to human needs and equal opportunities became the drive for development by the women (Van Zyl, 1994). The discussion focuses on addressing the second and third objectives of the study, namely, to determine the actions taken by the women and changes that occurred from participation in the research. Such actions had ripple effects into their families and the wider community, including practitioners and service providers. Two insights from the strategies the women used to overcome the oppressive nature of poverty and disability are shared and substantiated with literature.

- We challenge and change stereotypes of disability.
- We create a network of action spaces.

The dynamic interchange between the strategies is illustrated in Figure 11, which also gives the sub-themes of each insight. The diagram illustrates the point of engagement and the spiral effect of women's actions: as they challenge and change stereotypes, so they create action spaces, and vice versa.



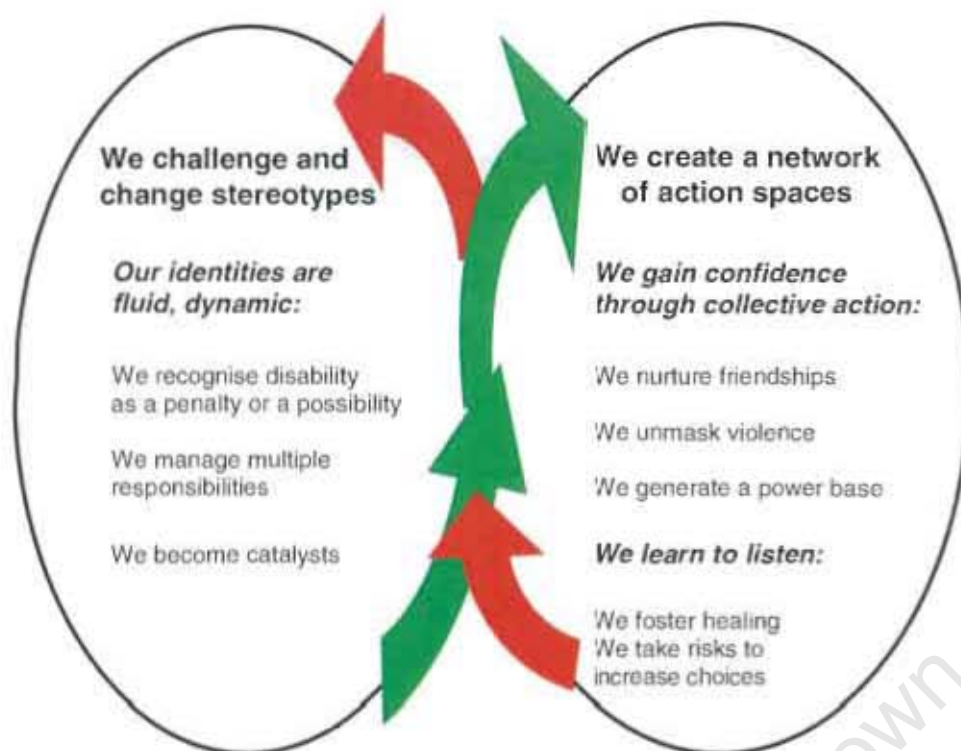


Figure 11: The dynamic interchange between opportunities and actions taken by the women

### **We challenge and change stereotypes**

The women realised that the stereotypes of disability created social barriers to their success at multiple levels. They recognised the need for a concerted effort to ensure that their voices were integrated in the struggle for equity and social justice. In exploring how the women challenged and changed stereotypes related to disability, a sub-theme was identified, namely, 'our identities are fluid and dynamic'. In challenging the stereotypes in this way, the women have dispelled the myths of dependency as women.

### **Our identities are fluid and dynamic**

In Chapter Five, we explored the tensions of loss and agency related to self-identity. Further findings revealed that the identities of the women were fluid and dynamic: their symbols and actions suggest that they are people who are resilient and self-reliant, they have abilities and integrity, and they are hopeful. These characteristics challenged the stereotypes commonly held by society about the identity of disabled people generally. It was evident that their own sense of self and collective identity did not fit necessarily with the way others viewed them. Vernon and Swain (2002) claim that the totality of a person's disability experience needs to be recognised and appreciated. They found that the experience of oppression was unique for different groups in Britain, which underpins different identities. Similarly, a study by Hill (1991 in Vernon and Swain, 2002) found that black disabled people in Britain were the most socially, economically and educationally deprived and oppressed members of society as a result of the extreme oppression they faced. Vernon and Swain (2002) comment that the fragmentation of identities occurs as a result of multiple sources of oppression, which is determined by the different reactions to impairment. The women's experiences



suggest that taking action to challenge and change stereotypes and stigmas has potential to consolidate or overcome this fragmentation.

### *We recognise disability as a penalty or possibility*

The complexity of the connections between poverty and disability were tackled in the action stories. The women recognised that their identities were multifaceted, as they changed over time through the contact that was established between them. They valued the differences that were sometimes positive as opposed to consistently being construed as negative. Thus it was important for the women to rediscover their own self-identity as a woman in order to value themselves. With fluid identities there appeared to be multiple penalties such as losses, violence and abuse, exploitation, poor health and discrimination related to the impairment. For other women, their impairment opened up new possibilities depending on whether they were able to access resources such as social security and self-employment opportunities. The women themselves recognised that they shared common ground with other women. At times, they even felt stronger than them. The fact that many women echoed the sentiment that their lives were "*even better ... I have even more*" was a testimony to their abilities and strengths, which have been clearly illustrated in the stories. It was difficult, and possibly unnecessary, to try to distinguish here what is general to women under poor conditions and what relates specifically to disabled women and how the one impacts on the other. They have the same hopes and aspirations of other women.

While the social barriers were significant, some of their limitations were directly related to their impairment (Thomas, 2004), which the women had to manage in a way that did not hinder their development. The women began to acknowledge the diversity of impairments within the group that led them to appreciate the differences in their experiences. Some women found their impairment and the disabling social barriers further aggravated the oppression they experienced as a consequence of poverty and race. There was a sense of resistance on the part of the women to accept the stigmas and stereotypes usually associated with disability, similar to findings by research accounts (Willmuth and Holcomb, 1993).

The dimensions of diversity and oppression, besides disability, were similar to those experienced by other women in impoverished contexts. French (2001, in Vernon and Swain, 2002) and Willmuth and Holcomb (1993) writing about disabled women as minority groups in developed contexts found that it was difficult to determine whether attitudes towards the women were related to factors of gender, race, class and disability. The nature of the interactions depended on different situations and the contexts, which either exacerbated or modified the experiences of discrimination. Nosek *et al.* (2003), who reviewed studies by Schaller and DelaGaza (1995) and Patterson *et al.* (1998), found that women shared work-related problems generally, including gender plus disability socialisation experiences and lack of role-models and mentors. Abu Habib (1997) has documented how amongst disabled women themselves, there are different interests, economic status, aspirations and life experiences, which confirms the experiences of the women in this study. These differences speak to the disability as an ever-present part of society. In the South African context, similar dimensions of diversity deepened the complexity of the disability experience. Such experiences showed that

there was not a single source of oppression. Human needs are the same in all contexts and historical times, whether the person has an impairment or not (Max-Neef, 1991). Equalising opportunities is a matter of political will and attitude. The social integration and participation of the women is, therefore, feasible, as lifestyles and support systems have been founded on social divisions, which the women have shown are removable. The essential insight reflected ways in which the tensions of deprivations are balanced as potentialities are fostered to afford equal opportunities for inclusion of the women in human development initiatives. It is sobering to absorb Roger's (1998) remark that, as a matter of scientific truth, everything in the material world is perfect, but the problem is our attitude towards it. Issues of difference were not seen as a barrier to participation, if the tensions were managed creatively. Where women's stories were in contrast to each other, there was a willingness to learn and grow from the differences, which enriched and strengthened the women.

### *We manage multiple responsibilities*

The action stories were testimony to improbable situations changing for the better. The stories revealed that the women were prepared to develop skills to manage resources to ensure that they were able to meet their family's needs. In working with the women, the facilitators came to realise the wisdom in Mama V's words: *'This project is very busy'*. One of the dangers that was identified was that the women were spread across so many activities that it made it difficult to find a suitable time to meet as a large group. Women had to focus and commit themselves to one or two initiatives, otherwise doing too many activities or having too many ideas was leading to fragmentation of efforts and a drain of energy. Being overextended prevented the women's progress to the stage where a profit was made. There was a strengthening of the desire and motivation for entrepreneurial success that was spoken about in the initial stories (see Chapter Five). By promoting the women's engagement in opportunities for skills development, we anticipated that the women would regain a sense of purpose and an ability to engage in meaningful activities.

Action-learning helped the women recognise areas of continued learning and personal growth as a means to their own financial success. Some of the women mentioned that they would like to improve their educational levels. In addressing the need for financial literacy training, the CoDEP project of SACLA and DPSA provided training on money management between the NAR workshops, specifically accounting and budgeting skills. Financial literacy training for business development was linked more with how the women managed their day-to-day budgets in their families to make it more accessible to apply to their business ventures. Reflections on these actions revealed that, because of the context of poverty, the risks of losing money were evident, as credit accounts were often not paid. In some situations, groups seemed to also lose their money as members of the group abused their responsibilities. There were times when the person who was appointed as treasurer left the group without an effective handover of the money or the books to another person. Other members responsible for marketing would not bank all the money. So the groups lost the small profits they could make and became frustrated. Kiyosaki and Lechter (1997:110) writing on gaining financial literacy comment:

I see one thing in common in all of us, myself included. We all have tremendous potential, and we are all blessed with gifts. Yet the one thing that holds us back is some degree of self-doubt. It is not so much the lack of technical information that holds us back, but more the lack of self-confidence.

Collective action would contribute to overcoming the oppression of poverty and disability, as we begin to value the power in diversity and accept difference as strength.

### *We become catalysts*

The women demonstrated how telling their story illuminated the stereotypes and biases related to disability in a way that provided support for collective action to address oppression and discrimination (Villa Vicencio, 1995). The women became catalysts as they confronted the barriers that hindered their participation in activities and events. They engaged in opportunities for skills development and occupational engagement that may not have occurred if they had not been disabled (Lorenzo, 2004). Attitude was recognised by Barberton (1998) as a significant obstacle to participation and development. Coleridge (1993) also claimed that change has to begin with those who want change: women and their allies. In a study of mothers of disabled children, Read (2000:49) also found that change of attitudes needs to be at a personal level first:

A number [of mothers] pointed out that before having their children, they had held attitudes about disability not dissimilar to those that they now found unacceptable. The majority had been uninformed or had given it little thought. The experience of bringing up a disabled child had changed all that and, in addition, ...it had the effect of making them more aware of other groups that they saw as vulnerable or likely to be given a raw deal.

Such shifts were important to take note of, as many attitude and advocacy campaigns are often aimed at changing attitudes at a community level first (Lorenzo 1999b; O'Toole and McConkey, 1995; Werner, 1995). It is often the fears and uncertainty of the unknown on the part of officials and practitioners that hindered the integration of the women (Thomas, 2004; Reeves, 2004; Lorenzo, 2003; Marks, 1999). Meer (1998) acknowledges that it has always taken courage for other women to talk about personal struggles in their lives. The struggles she cites have much in common with the women in this study. Generally, women have identified their 'real' fight as a struggle against a patriarchal society and cultural practices, which need to change. Thus the burden and struggles of the women in this study were seen as both private and political struggles that affect most women and limit their opportunities:

For the sake of peace in the home, many strong women choose to ...ignore the oppression they face in their homes. But in fact, it is this struggle, which is central to our daily lives and liberation ... these struggles demand changes in our attitudes, the attitudes of our families and the attitudes of the men we live with and love (Meer, 1998:96-97).

This insight from the stories of actions confirmed Vernon and Swain's (2002) contention that evolving identities occurred as a consequence of disability experience. In exploring the multiple oppressions that black disabled women in the United Kingdom experienced as an ethnic minority, they found that there was a need to negotiate spaces that contribute to overlapping identities. People are willing to change, but it requires the efforts of advocacy and mediation (Read, 2000). Inclusion in development as a measure to equalise opportunities would be feasible, as oppression is a common experience amongst women. The next insight speaks about how the women were able to create a network of spaces for their inclusion into local development initiatives.

### **We create a network of action spaces**

The action stories demonstrated that the perceptions and misconceptions were challenged and changed by women getting to know each other through a variety of interactions: home visits by the CRWs, groups, workshops and community meetings and events. Writing on the situation of poor people in the new South Africa, Barberton (1998a:3) advocates that

creating action spaces...seeks to encourage people to think about and debate how the challenge of poverty and democracy... might be achieved by doing some things differently... to establish a more just socio-political, economic distribution of power.

He contends that the nature of action spaces is transformative and democratic; the spaces push the boundaries and question policies; and from these action spaces, people may initiate projects or programmes. From these newly created action spaces, the women engaged in an inward and outward journey of conscientisation regarding their beliefs and values (Lorenzo *et al.*, 2000; Lorenzo *et al.*, 2002). In this insight, two aspects that illustrate vividly how the women create a network of action spaces to equalise opportunities in development are described, namely, "We gain confidence through collective action" and "We learn to listen". (Refer to Figure 11 for sub-themes.)

### **We gain confidence through collective action**

Motsei (in Meer, 1998) calls for all women to build the confidence amongst themselves, so as to reclaim their strong voices during the time of reconstruction, which is difficult and needs hard work. The emotional growth that happened for the women was seen in the creation of networks that helped lighten their load. The women valued collective action as a means of skills development through sharing and learning together. The support amongst the women and facilitators seemed to generate confidence in the women, but it had to be balanced with the risk of creating dependency. The shift in power dynamics was also apparent between the CRWs and the women who began to openly express emotional changes that they noticed. They hoped to improve co-operation in the group so as to strengthen collective action. Barberton (1998) found that obstacles to organisation hampered participation in democratic processes and structures. Housework and

childcare were found to be factors that prevented the women from organising, as well as lack of education and training. Meer (1998) affirmed our convictions that building the future by organising and sharing together under the new system of government could provide everyone with an equal chance to a decent life. Ensuring such accountability had potential to contribute to the ongoing development and sustainability of the women and their initiatives. It was important to create action spaces for the resolution of conflict in order to create a group climate conducive to collective action. With increased self-confidence, the women changed their own beliefs and feelings about disability, as well as being catalysts for change at family and community levels. The perseverance and determination visible in the strategies of the women to succeed were reflected in their actions, as they built social and political networks of trust, for co-ordinated, collective action towards human development (Buckland, 1998; Taylor, 2000). While these measures of social capital determine the degree to which disabled women as a community, work together effectively so that their voices are heard and their desired results achieved, Tutu (2004) advocates the concept of social harmony: people working together create a harmony that moves them towards achieving their vision. The women gained confidence, as catalysts and advocates of change, as they encouraged each other to speak to family and community members so as to change the situation for the better. Their change found expression in new friendships that developed out of the research process.

### ***We nurture friendships***

Telling stories about their everyday activities and the different opportunities for skills development that they engaged in revealed the emotional changes that the women experienced. They gained confidence through friendships that formed during the PAR study. The newfound friendships increased self-esteem and self worth. Identity as a matter of 'becoming' and not simply 'being' was evident (McColl *et al.*, 2000; Thomas, 1999; Townsend, 1998; Wilcock, 1998). Human needs were satisfied as the women experienced a sense of belonging. Hudson (1995) spoke of "gifts of friendship" that are developed through individual and collective struggles, as "belonging signposts the route towards becoming" (Hudson, 1995:80). Such friendships occurred as they overcame their sense of personal isolation and engaged in actions. The experiences echoed the words of Gueye (1999) that no future or African Renaissance could be envisaged if people felt psychologically defeated because they had lost their confidence in themselves and their ability to change their own situation according to their own needs. Many writers on development in South Africa have found self-confidence to be a key to capacity development and sustainability (Hope and Timmel, 1995; Kaplan, 1996; Meulenberg-Buskens, 1996; Roodt, 1995; Taylor *et al.*, 1998). Support and trust was built as friendships developed. The women regained self-respect as they learnt to recognise latent potential within themselves and others. There was a growing self-awareness about their abilities to provide for themselves and their families as well as to re-engage in familiar and known roles. Women remarked on the renewed dignity they found from participating in cultural ceremonies again. Regaining respect produced a strong sense of hope in the women that they would succeed.

### ***We unmask violence***

Telling their stories gave the women the strength and confidence to support each other with problem-solving in different contexts. The women spoke about different interactions where mediation was necessary, which

were similar to the ones encountered by Read (2000): family and friends; encounters in public places; work directly with disabled children and negotiations with services. The CRWs, both as service providers and mothers of disabled children themselves, also helped to create action spaces where different interactions were mediated. As research facilitators, we were often overwhelmed by the high incidence of violence and abuse experienced by the women. Creating networks of action spaces had potential, as synergistic satisfiers (Max-Neef, 1991) to meet many of the human needs of identity, affection, understanding, protection, participation and freedom, which had been violated by various forms of exploitation.

Mmatshilo Motsei (Meer, 1998) identified similar issues confronting women generally, particularly violence, economic empowerment and literacy. Yet, the literature review revealed that there is very little recorded of the prevalence of violence related to disabled women specifically. Even though a number of organisations have been set up to fight the violence, the police and legal systems seem ineffective in helping the women to deal with the perpetrators. The literature indicates that the violent behaviour of men comes from racism and poverty due to the history of our country as respect and dignity have broken down (Abrahams *et al.*, 1999; Meer, 1998). According to Telela (1994 in Meer, 1998), many traditional ways of dealing with such marital problems have not taken into account the way the women feel or think. The women most frequently asked for more advice about dealing with violence, which suggested that the community structures they reported were ineffectual. Thus the women were often left isolated in their homes or had tried to fight the violence alone. Meer (1998) stated that men were socialised to believe that real men are able to control women by being aggressive and violent. As such, South African structures, institutions, cultures and practices (which are male-dominated) justify, maintain and reproduce violence. By creating action spaces for the women to speak about their experiences of violence that occurred in different forms, they were able to break the silence and receive support and solutions from others who had similar experiences. Motsei (in Meer, 1998) expressed a need for grassroots-based community empowerment to make sure women are active participants in the development process in the social, economic and political arenas. DPSA organised several workshops with consultants on these issues.

### ***We generate a power base***

Hope in the future lay in women making their voices heard through organising collectively so that negative attitudes about disability were uprooted. Information sharing was as a key strategy to create group cohesion for collective action. Mallie Fakir (in Meer, 1998) urged us that women should not fool themselves about the power that lies in politics: unless women get involved in the political processes, they will get left behind. The women needed adequate time and opportunity to access information that service providers already have through participation in discussions, meetings and decision-making. They needed time to learn how organisations work and the way that services are set up. Thus the challenge was to find ways that the women were able to act together, not once but consistently, to get ahead collectively (Carroll in Buckland, 1998). The building of social harmony required investment of trust and social skills of all players in the process. A pattern of interactions between the women and the CRWs, as well as the research facilitators, raised tensions related to the roles different stakeholders assume, or maybe more accurately, that they move between. Their emotional growth enabled the women to build strong, reciprocal partnerships (social harmony) with other disability



organisations, civil structures and health and social services, which would contribute towards human development.

The disability rights movement prioritises the development of community-based support systems to provide an organised power base for disabled people from which to build a partnership with professionals (Finkelstein, 1993; Coleridge, 1993). The Disabled Women's Development Programme of DPSA provided a power base from which the women were able to organise themselves and access opportunities (Cilliers, 2004; Cockburn, 2003). Marjorie provided a strong role-model, which enabled other women to become catalysts of change as well. The number of positive role-models among the women themselves multiplied (see more stories of change in the appendix 14). There was also appreciation for the role of SACLA's CRWs, themselves mothers of disabled children, as catalysts of change. As research facilitators, we were able to request that the CRWs report critical issues at their weekly team meetings. Following these reports, counselling and home visits with one of the practitioners such as a social worker or occupational therapists at SACLA or another NGO was arranged. DPSA was also able to organise relevant workshops in response to the expressed needs, which strengthened the women's strategies used to carry their load. Lorenzo, (2002) found that structures such as disabled peoples organisations, parents' support groups, playgroups or day care centres, and income generation projects provided an organised power base for disabled people from which to build a partnership across different sectors.

There was always the risk that the dynamic in power relations between the women and research facilitators could lead to mutual deception because of the hope of gaining something, or fear of penalty. The practice of participation sometimes felt cosmetic where the right language or terminology was used, but there was little change in behaviour. These cross-cultural matters contradicted Townsend (1995) who commented that marginalised people showed great faith in the power of the written word and the power of experts. While the women respected one's level of education, they were cautious of their vulnerability to exploitation, and traditional cultural values were paramount. Older people were shown respect by younger people. We remained open to the women questioning us, and being accountable to the group in decision-making processes (Flower and Wirz, 2000). Women grew in their ability to listen, which had positive ramifications for collective action. Nelson and Wright (1995) comment that participation involves looking at a shift in power and working in partnerships. Power in this sense was seen as a description of a relation, not a 'thing' that people 'have'. The women's stories illustrated how practitioners and disabled people stand in relation to each other in the different systems (political, economic, family) that are described as power. In the national context, political changes have not been matched by economic improvement for women generally (Meer, 1998). Creating a network of action spaces involving similar projects strengthened the women to achieve in their initiatives. Such collective action was common among women generally during the struggle against apartheid (Meer, 1998). Stokvels<sup>23</sup> were another common strategy of collective action in the Black communities as a way of building up seed money or initial capital to offset a new business venture (Broodryk, 2002). The groups used

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<sup>23</sup> A traditional means of collective savings where each member contributes monthly, and one member receives the savings on a rotational basis.

the same strategy to collect money from each member of the group, which ranged from R5–R30, on a monthly basis as a means of building up capital. Each group appointed a supervisor and treasurer to keep account of the funds. While women such as domestic workers, farm workers and informal sector workers have organised into various unions in the 1990s (Meer, 1998), it was apparent from the women in this study that they remained unaware and segregated from the trade union movement. Unfortunately, the new legal changes in South African laws such as the Labour Relations Act, the Basic Conditions of Employment Act and the Employment Equity Act had not yet been translated into reality for the women in this study.

### **We learn to listen**

The energy, enthusiasm, vigour and animation that developed amongst the women were often tangible in workshops through their spontaneous singing, dancing and testimonies of change. The abilities of women were unleashed in the silent spaces created through the action of listening and reflecting. Listening was seen as a valuable resource and skill that everyone could acquire without needing vast material resources (Slim and Thompson, 1993; Broodryk, 2002). Such safe, spacious and sacred spaces for self-disclosure and honest communication were essential to progress (Hudson, 1995; Tutu, 2004).

### **We foster healing**

The power of learning through listening to each other helped to heal the relationship between the women and their siblings, spouses and children. Peck's (1987) four stages of community-building were relevant to the women's process of creating a network of action spaces that would foster healing<sup>24</sup>. There was an honesty and truthfulness as women shared their stories, listened and responded to each other in a way that generated respect and dignity. Roger (1998) maintains that losses may open up opportunities. Negative experiences related to disability were healed through engaging in everyday activities. The sense of solidarity and reciprocity that developed during the workshops emerged as they began to participate in local development projects with other women (Lorenzo *et al.*, 2002; Lorenzo, 2004). Their sense of isolation was broken as they found their voice and shared compassion.

### **We take risks to increase choices**

Risk taking also grew as the women discovered more strategies to meet their needs collectively. Flexibility in the workshops helped explore the dynamics of dependence, helplessness and vulnerability as power. The women recognised the changes that happened through their own actions. They took the risk of showing their vulnerability while honouring the dignity of others. Based on insight gained from Chamber's writings on rural development (1983) and challenging the professional boundaries (1993), as well as the action-learning

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<sup>24</sup> From initially being very polite and friendly (pseudo-community), the women became more open with each other, as they took more risks in challenging one another's assumptions and appreciating each other's vulnerability (chaos). Together, in time, barriers to communication, which are categorised into five groups: perceptions, stereotypes and biases; expectations; differences in ideologies, theology and belief systems; the need to fix, heal and solve; and lastly, the need to control were recognised ('emptying'). Emptying of these barriers between all stakeholders facilitated inclusion into mainstream initiatives. Many women spoke about the cohesion that developed amongst them since speaking about their joys, embracing their pain from their struggles and celebrating their successes (true community).

approach of Hope and Timmel (1995) and Schon (1991), we reversed the way we taught, learnt and evaluated progress in order to change the situation of poor people. We learnt the importance of embracing mistakes by sitting, observing, asking, listening and reflecting on everyday practice and seeing the women as active participants rather than passive recipients (Lorenzo, 2003; Priestley, 1999; Read, 2000). Real empowerment and self-development happened when the women were given the “space and freedom to fail and learn from their failures on their own” (Coleridge, 1993:113). Such flexibility in working together allowed for exploration of a diversity of needs and ideas. The approach also encouraged exploration of different experiences and perceptions of power in partnerships between professionals and DPOs (Lorenzo, 1994; Miles, 1996; van Niekerk *et al.*, in press; Werner, 1995). In this way, an attitude of ‘cognitive respect’ on the part of the research facilitators (perceived as the more educated and more influential) towards the women was encouraged (Chambers, 1993).

## REFLECTIVE SUMMARY

The action stories challenged the stereotypes and stigmas related to a disability identity. Small changes were happening all the time, from one workshop to another, both at an individual and collective level. The strength in their identity could be contrasted with the vulnerability that one would usually expect. It was evident that the women found inward strength by gaining confidence through friendships that developed as a consequence of a network of action spaces. The women’s ability to change their personal circumstances and recognise changes in others increased.

The women appreciated the power of listening to one another’s stories. Learning to listen reinforced the importance of building supportive, inclusive communities where personal development and emotional well-being could be nurtured (Broodryk, 2002; Tutu, 2004). Tutu coined the term ‘social harmony’. The most valuable resources the women discovered were the human experience and human spirit that gave them the ability to take risks. The language of light dispelling darkness and bringing hope was evidence that they became catalysts for change. The stories evoked images of healing and well-being, as we learnt to listen and take risks.

The NAR workshops have shown that if women can be helped to become competent participants in their own rehabilitation and development within the community, as well as people who have some hope and aspirations, then they will no longer be isolated and dependent. The relevance of the NAR workshops in disability research is explored in more depth in Chapter Eight.

### PLANNING FOR FURTHER ACTION: SUGGESTIONS

I was aware that action-learning would enable the participants to come back from training workshops and share what they have learnt from others so that there was an effective multiplying of skills (Hope and Timmel, 1995; Taylor *et al*, 1998). PAR provided an opportunity for the women to take more control over their own lives. Spaces for reflection on actions need to be created continuously to ensure sustained change. I found myself confronted by questions related to sustainability that came up frequently: What did the women need to sustain themselves economically and socially? Did they have the ability to sustain their initiatives in business development in the context of poverty?

Seeing the positive self-image that emerged in exploring the women's identity, the question arose for the facilitators about whether it was significant that SACLA was a faith-based organisation? Or is their faith not what makes them feel better? Was it the opportunities for training and employment and having meaningful roles to fulfil and their spirituality generally that made the difference? That these women have survived is a testimony to their resilience, inner strength and spirituality of struggle.

The women claimed: "*We don't see ourselves as different!*" The multifaceted nature of disability and development, which incorporates a web of possibilities for disabled women, incorporates a spirit of interdependency and a spirituality of disability, which is discussed in the next chapter.

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## Chapter 7

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# The Web of Possibilities for Disabled Women: Thesis Building

### Introduction

#### **PART 1: An *Ubuntu* approach to disability**

##### **Promoting the interdependency of *Ubuntu***

The connections between self and collective identities

Advocating for inclusion in human development

From dependence to interdependence

##### **Defining a spirituality of disability**

Potential, choices and hope

Nurturing emotional resourcefulness

#### **PART 2: Narrative action-reflection workshops: pioneering a new method**

##### **Potential to generate data about collective experiences**

A means of asserting and promoting humanity

Readiness of participants to question themselves

Permanent openness of mind

A capacity for assimilation and adaptation

A capacity for creativity and innovation

A spirit of rigour, organisation and method

Combine emotion and reason in our responses to development

##### **Was there emancipation through participation?**

### Reflective summary





University of Cape Town

# The Web of Possibilities for Disabled Women: Thesis Building

## INTRODUCTION

The participatory action research study with the disabled women in Khayelitsha took place in a context of political, social and economic transition in South Africa. The peaceful transition from social oppression by the apartheid regime to constitutional democracy has been hailed internationally as a modern miracle. The miracle has been attributed to the survival of the *Ubuntu* spirit by the masses (Broodryk, 2002). A spirit of liberation fuelled the transformation of the South African socio-political order, based on the values of tolerance, peace, love and compassion of *Ubuntu*. These values are the same in all cultures, but the manner and intensity in which they are manifested are different (Broodryk, 2002). These values cooled the fires of justified anger and potential violence, especially when the Truth and Reconciliation Commission unmasked the intolerance and oppression of apartheid (Broodryk, 2002; Mosala, 1995; Tutu, 2004). A connection, albeit different in degree and prevalence, may be drawn between the experiences of black people during apartheid and black disabled people, especially women, who are marginalised and excluded not only on the basis of race, but of ability and gender. The transition to democracy in South Africa, in effect, also meant the transition to liberation for disabled people. The core principles of our constitution recognises the inherent dignity of every man, women and child, which needs to be respected and protected.

The previous chapter alluded to my first thesis that, in Africa, approaches to disability need to encompass *Ubuntu*, so as to ensure inclusion of disabled women in human development (Broodryk, 2002; Tutu, 2004). In Chapter Seven, I present two parts to building the thesis of this study.

1. I advocate an *Ubuntu* approach to disability, based on the values and concepts of *Ubuntu* (Broodryk, 2002; Mbigi and Maree, 1995; Mbigi, 1997; Tutu, 2004) that were revealed in the women's stories.
2. I propose that narrative action workshops provide a dynamic and interactive method for generating data of disability experiences collectively, as well as a strategy for equalising opportunities in human development. The method has potential to contribute meaningfully to social change through the incorporation of African values of *Ubuntu*.

# Part 1

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## AN *UBUNTU* APPROACH TO DISABILITY

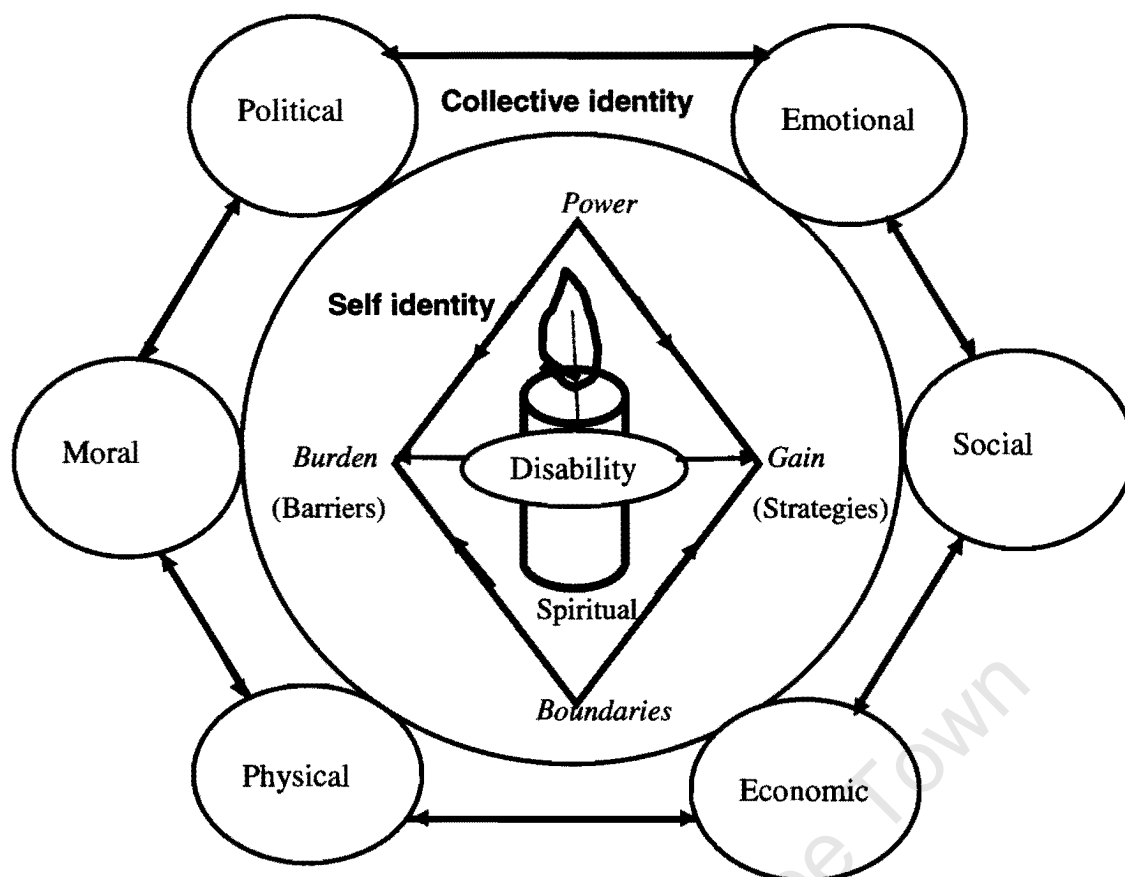
Currently, the social model of disability focuses on theoretical debates in disability studies to address social oppression through social policy and legislation (Barnes and Mercer, 2004). The findings suggest that the social model appears to have limitations in poverty-stricken communities where there may not be resources and support to advance policy implementation. Thomas (2004) suggests a social relational model of disability that responds to the impairment effects and psychosocial consequences as well as social barriers. I now substantiate my proposition by presenting two propositions in the quest for social change for disabled women:

1. Promoting the interdependency of *Ubuntu*
2. Defining a spirituality of disability

### Promoting the interdependency of *Ubuntu*

I base my first thesis on Broodryk's (2002) **interdependence** of self-identity through the collective identity of *Ubuntu*. I propose that change is ignited when human development initiatives move beyond policy orientated and social relational interpretations of the social model of disability (Barnes and Mercer 2004, Thomas, 2004) towards harnessing the power of interdependency within a human rights framework. I argue that an *Ubuntu* approach to disability will take existing models a step further, as it seeks to foster Afro-centric values in civil society and public servants in response to disability, where human beings are valued as equal (Broodryk, 2002; Tutu, 2004). Equal attention has to be paid to the concept of interdependence of *Ubuntu* in human development in order to achieve social inclusion and equal opportunities for disabled people at an individual and a collective level.

The age-old African philosophy of *Ubuntu*: "*umuntu ngumuntu ngabantu*" means 'a person depends on persons to be a person' (Shutte, 1993; Tutu, 2004). *Ubuntu* refers to the humanness and wholeness of life, the Divine image in a person (Koka, 2002). Thus the women are people through other non-disabled people, and vice - versa. An *Ubuntu* approach to disability would tackle the root causes of oppression and discrimination experienced by disabled women. Figure 12 depicts the critical dimensions of the *Ubuntu* approach to disability that emerged from the findings, as central to the women's stories of action and change through sharing experiences collectively. Tutu, (2004) claims that *Ubuntu* encompasses the struggle for social harmony. Thus this approach would operationalise the possibility of reducing poverty, as human needs would be met through the participation of women in different opportunities for human development, which is multidimensional, that is, spiritual, social, economic, political, emotional, physical and moral. Moral development is linked to the rights-based approach of the UN Standard Rules (UN, 1994) as well as the human relations nature of *Ubuntu* (Broodryk, 2002).



**Figure 12: Interdependency and spirituality - Critical dimensions of an *Ubuntu* approach to disability**

Self-identity forms the inner circle because in African life, a person is the most important element of a society, and forms the cornerstone of society as an inherent spiritual being. As such, a person is dependent on the goodwill and acceptance of others, which creates an inclusive society (Broodryk, 2002). Disability is a burden or penalty when it is experienced as a loss of power or imposed boundaries within society. Disability as a gain or possibility occurs when the myths of disability are dispelled and the boundaries extended. Collective identity comprises six circles connected by two-way arrows to represent the interplay between the dimensions of human development, which include social, economic, political, as well as spiritual, emotional and moral. The circles are all connected to the inner circle to indicate that no person can survive as an individual, whether disabled or not. As we recognise the human poverties that we experience at an individual level, so we can identify actions collectively that will build solidarity to enable disabled people to challenge and stereotypes, as well as create a network of action spaces for their inclusion in opportunities for human development. I contend that the three dimensions of emotional, spiritual and moral development are not addressed explicitly in development programmes. In a study in Uganda, Whyte and Muyinda (2002) found that immobility of disabled people was broader than just physical, which once addressed, extended to other dimensions of mobility such as social, political and economic. The interconnections between these dimensions (as depicted in Figure 12) reveal the complexity and interplay between self and collective identities – if the collective identity is ignored in human development initiatives then self-identity is hindered.

The candle is placed within the diamond, as a diamond refracts light. In their drawings, many of the women depicted burning candles bringing light to their darkness as a source of strength and hope. In seeing themselves as light, the women realised their ability to draw on their inner resources as an essential source of energy. The body of the candle represents disability, the wick the potential of women to overcome the burden, if a catalyst such as information, transport, support, and dispelling myths acts as a match to light the candle. As the light shines, it diminishes the darkness and extends the boundaries. Simultaneously, as the candle burns, the wax diminishes, in the same way that the burden of disability diminishes as the women overcome isolation, challenge and change stereotypes, and create a network of action spaces through social reflexivity and collective action (Broodryk, 2002; Giddens 2001). The capacity of women, children, families and neighbours to understand disability issues is nurtured. As power increases, so they extend their boundaries for human development and vice - versa. Human relationships and interactions are paramount – the essence of being a person through other people is illustrated in the different critical dimensions that comprise the collective identity (see Figure 12) - and shaped the women's conception of themselves as people. The spaces and connecting lines in between the self and collective identity are dynamic and constitute my second thesis about the power of NAR workshops in promoting social reflexivity, which is addressed in the second part of thesis building in this chapter.

I now substantiate my first thesis by suggesting three ways in which a web of possibilities may be created within an *Ubuntu* approach.

### ***The connection between self and collective identities***

A web of possibilities influences self and collective identities, which are formed through human relations and interactions. *Ubuntu* acknowledges the right and responsibility of each person to promote the well-being of individuals and society. Women made clay sculptures of different animals to depict the changes in their identity. Some of the women used the image of a cow. An analogy of two cows illustrates the understanding of *Ubuntu* through the concept of 'sharing with the other':

If you have two cows, and the milk of the first cow is enough for your own consumption, *Ubuntu* expects you to donate the milk of the second cow to your underprivileged brother and sister. (Sisulu, 1993 in Broodryk, 2002:1)

Thus if I possess numerous skills, *Ubuntu* expects me to share them with the suffering masses at a grassroots level, that is, women who are oppressed and discriminated against (Broodryk, 2002). A high value is placed on human worth found in communal contexts, which encourages co-operation in a spirit of sharing and caring, rather than the individualism of the West. Thus the essence of an *Ubuntu* approach is the spirit of interdependency. The interconnections between the personal (individual) and the social (collective) are often neglected in programmes with disabled people. Little attention is paid to social reflexivity, which was described by Giddens (2001:668) as "the two-way process by which we shape our social world through our individual actions and are ourselves reshaped by society". Structuration describes the praxis between self-

identity and collective identity that becomes dynamic and, therefore, socially transformative. Income generating projects, for example, focus more on skills acquisition than on the development of self and collective identities. I argue that a strong self-identity formed through collective identity lays the foundation for political and social growth that will sustain economic development, not only for women as individuals, but for their families as well (Broodryk, 2002; Kretzschmar, 1995; Tutu, 2004).

The barriers described in Chapter Five suggest that in some families, the values of *Ubuntu* have been lost in the interactions between the women and family or community members (loss of power, disability as a burden and imposed boundaries). In contrast, the strategies showed the ways in which the women contributed to rebuilding *Ubuntu* (dispelling myths, disability as gain and extending boundaries), as they adjusted to the numerous losses, emotional changes, stereotypes and biases of disability. Chapter Six described how the women challenged and changed stereotypes further by creating a network of action spaces. The interplay between deprivations and potentialities, which shape the individual and collective identity, was witnessed again. Their self-identity shifted from alienation towards inclusion, as collective identity was shaped through interactions developed through the study. In appreciating the interdependence of the self-identity and collective identity of the women as the essence of human development, the women began to advance equal opportunities and inclusion.

#### ***Advocating for inclusion in human development***

A web of possibilities advocates for inclusive development as the core to transformation and human development. *Ubuntu* fosters a sense of belonging and inclusion in the spirit of family, as it reinforces the development of self through others (Broodryk, 2002; Shutte, 1993; Tutu, 2004). The extended family has been recognised as a central aspect of African life (Broodryk, 2002; Tutu, 2004). The development of a strong sense of self through emotional, spiritual and moral development enabled collective action in the political, social and economic spheres of life (Bauman and Tester, 2001; Giddens, 2001). The changes experienced by the women during the study resonated, not surprisingly, with the values of *Ubuntu*, namely, humanness (dignity), respect, solidarity, compassion and survival (caring and sharing) (Broodryk, 2002; Mbigi, 1995; Shutte, 1993). The values of *Ubuntu* reflect the collective nature of African philosophy and spirituality (Khoza, 1999). These values promote inclusion. As mentioned earlier, these values maybe the same in other cultures, but the intensity of them is unique to African culture (Broodryk, 2002). This characteristic links with the fundamental human needs, which are also seen as the same in all cultures and historical times, but the satisfiers differ between cultures (Max-Neef, 1991; De Wet, 2002). Flexibility is required rather than rigidity to create an environment of non-discrimination (Bauman and Tester, 2001). *Ubuntu* fosters inclusion, as people see each other as human beings, equal, with aspirations and hopes of a better life. Compassion is found in solidarity. As in any family, moments of tension in development occur, as issues of power are negotiated and resolved, increasing openness and frankness amongst the members, and extending boundaries.

The reawakening of the African Renaissance calls on everyone to deal with the challenge of building a new life based on African ideals and way of thinking, regardless of intellectual background or academic skills



(Gueye, 1999). The women have shown that faith and hope gives them the strength and courage to face the challenges and the long journey towards their inclusion in society as a contribution to the transformation of our country and the African continent. Many women experienced a renewed sense of power at home. They saw themselves as providers of light to other disabled women as they have regained their dignity as women. So, for now, to paraphrase the words of sponsors in Makgoba (1999) is the challenge: If the African Renaissance is to be the renewal, rejuvenation, and recreation of Africa in the hearts and minds of all who know her, love her and still seek to discover her; if it is to rekindle the Spirit of innovation and resourcefulness of her people; if it is to be a process of rebirth, renewal, revival even rededication, **then** disabled women need to be an integral part of any development process. The stories provided evidence of the feasibility of inclusion of women in mainstream development initiatives.

### ***From independence to interdependence***

A web of possibilities informs the need to change the goal of independence in rehabilitation to cultivate a spirit of interdependence. The African pot transcends the boundaries of different cultures in South African. It is round in shape and comes in various sizes. The pot is made of cast iron, with three small legs that are not in proportion to the roundness of the pot, with a lid and handle. It also takes very little fuel to cook as the pot retains heat from a fire using twigs and small pieces of wood is continuously feed to the fire beneath the pot. The cooking is a slow, long process, at low temperature. The use of the pot is versatile, from steamed bread, pap (stiff maize porridge) and meat stews. The method of cooking varies, but basically one or two women will use wooden spoons of varying sizes to stir the contents in circular movements. Cooking is a central and essential activity in any family, as well as ceremonies and festivals, and meets many of the human needs, as it is a communal activity.

The African pot (pitseng) was a symbol of interdependency that emerged early on in the study in the clay sculpture of one of the CRWs. She made a clay sculpture of an African pot to described the PAR process, as the three legs symbolised the CRWs, the women and the facilitators as the participants in the study. The three legs were also representative of the tensions of interdependency that need to be balanced to foster inclusion – at an individual level, the connections between identity, potential and inclusion; while at a collective level, the connections between the individual, family and community; as well as the individual, family and practitioners in public health services, particularly rehabilitation professionals. This concurs with Ingstad's (1995) concept of the 'disabled family', which promotes the idea that impairment and disability will impact on the family and not just the individual.

The White Paper On An Integrated Disability Strategy (ODP, 1997) calls for all leaders and stakeholders in a community to be integrally involved in changing attitudes and removing barriers to participation by challenging negative beliefs and stereotypes to disability. This call includes the need for more recognition of disabled women as potential catalysts for change to promote their integration. They would be able to influence a change in beliefs about disability in the communities. A realisation that even though life-skills for self-development may form part of the rehabilitation process in hospital, it is not a once-off event for an individual. Life-skills development

would need to be ongoing once the women are back in their community to facilitate equal access to resources and opportunities as a means of reintegration into social life of their families and community. Thus the goal of independence in rehabilitation process needs to be revisited in the light of Ubuntu, which seeks to cultivate a spirit of interdependence.

Chamber's writings on rural development and poverty continue to deeply challenge and influence professional boundaries of practitioners and researchers. His writings often echoed the sentiments or struggles that we faced, and put words to our experiences. As practitioners and researchers involved in disability that is attempting to address poverty and the barriers to opportunities for development, we are faced with the dual challenge of ensuring relevant service delivery, teaching and research. Chambers (1995:42) describes eloquently the nature of the challenge and changes that face us:

The new challenges for the 21<sup>st</sup>-century face the rich and powerful more than the poor and weak, for they concern reversals, giving up things ... for uppers to give up dominance at the personal level, putting respect in place of superiority, becoming a convenor and provider of occasions, a facilitator and catalyst, a consultant and supporter, is less difficult ... perhaps one of the biggest opportunities now is to enable more and more uppers to experience those satisfactions personally, and then themselves to spread them upwards, downwards and laterally to their peers.

Chamber's comment demonstrates the dynamic nature of this interdependence in meeting human needs that have been spoken of so strongly (illustrated in Figure 12), as the means to human development, not only for individuals but for families and community as well. Gueye (1999) warned that a genuine African Renaissance is impossible without a radical change in the way we face our daily problems and behave amongst ourselves. How much more so in the way we approach disability in rehabilitation programmes and human development! Lang (2000) argued for an alternative model to the social model of disability that would show the dynamic nature of interactions. He identified social change, human nature and development as the three components of an alternative model. These components were strongly illustrated in the changes the women experienced, but went further to suggest that spirituality influenced human nature, development and social change. Both individual and collective needs are formed through human relations and interactions. Fox (1995) proposes a spirituality of work, a dimension that is often not recognised in academia, the workplace or development practice. As the literature review revealed, spirituality has been absent from the academic discourse on disability and development in the training of public health practitioners generally as it is seen as a taboo subject (Christensen, 1997; McColl *et al.*, 2000; Rafi and Chowdhury, 2000). The spirit of *Ubuntu* provided hope and a potential for the women to develop networks for collective action. A **spirituality of disability** forms an integral part of the *Ubuntu* approach to disability, as it provides the impetus for change at a dynamic level between the intra-, inter- and transpersonal levels (McColl *et al.*, 2000), which will hopefully have reinforced changes at a policy level and a social relational level regarding disability.

## Defining a spirituality of disability

The second aspect of an *Ubuntu* approach to disability encompasses a 'spirituality of disability', which illustrates the dimensions of personal and social change that both mirrored the values and manifestations of *Ubuntu*, and contributed to a strengthened self and collective identity in the women. I attempt to show how Thomas' (2004) construction of disability identity, which takes into account that the personal is political, and her contention that the psycho-emotional aspects of impairment need to be recognised, could be extended by appreciating the spiritual aspects of a person's identity. An understanding of a spirituality of disability that emerged for me during the study was rooted in the exploration of individual and collective beliefs and convictions connected to our values about disability, and our lives. These values inform our behaviour towards one another and ourselves. *Ubuntu* reflects the image and likeness of God in each person (Tutu, 2004). As human beings, we are continuously involved in interactions with each other. Spirituality provides a driving force or energy to live a meaningful and purposeful life, and recognition of a Higher Power or Being. Hudson (1995) suggests that there is a need to nurture a spirituality that shows concern for personal needs together with a struggle for social justice. I realised that the experience of disability initiates an inner journey of exploration of our beliefs and values, which often leads to a change outwardly. There is a realisation that 'I' am not ultimately in control – a spirituality of disability is about an initial surrender of control and change in beliefs and values that occurs. Thus I propose that spirituality is at the core of human development for disabled people. Disabled people's growth is exponential as they find their voices and participate actively in decision-making. As such, taking risks conscientises them to the realities and the struggles for social justice and equity for all, enhancing their moral development. Two aspects of a spirituality of disability are explored in more depth here.

### *Potential, choices and hope*

A web of possibilities mirrors the cyclical connections between potential, choices and hope of human nature, inherent in the spirituality of an *Ubuntu* approach to disability. Throughout the research process, the women created a link between their beliefs and values in God as a source of strength and God as a provider for their economic empowerment. Liberation theology has suggested that God is the God of the poor and the oppressed, as both Mosala (1995) and Tutu (2004) exhorted during the apartheid struggle. Eiesland (1995) extended this notion to the idea of the God of disabled people as well, as she claims that God depicts the vulnerability and imperfection of mankind in Jesus in the same way that society sees disability as a symbol of brokenness, vulnerability and imperfection. I suggest that in sharing our vulnerabilities, we ignite the latent potential in ourselves to perform familiar and new roles. Being aware of the choices will connect us with the inherent hope for change, as beliefs and values about disability are reshaped. By embracing the pain of loss, and recognising latent potential and hope, we connect to personal power. I concur with Bauman (Bauman and Tester, 2001:5) who points out that we are all called to understand a world that is not our own, "to live for the other" and to respect their dignity. Bauman suggests that moral development is about people as humans, and how we interact with each other. This aspect forms the essence of spirituality in *Ubuntu*, the

approach of Human Scale Development and the principles within the Standard Rules. Bauman goes on to comment that the possibility of humanity is our choice, which makes all the difference. Morality lies in our humanity and human dignity, which is determined by the choices we make and our commitment to the other over time (Bauman and Tester, 2001).

The hope that the women inspired was similar to the freedom that other women found in their spirituality (Mosala, 1995; Kretzschmar, 1995). Kretzschmar (1995) comments that faith and hope provide an important means of support for oppressed groups. From her research in Botswana, Ingstad (1997:202) suggests “success” refers to “freedom from problems and struggles”. This resonated with the women’s experiences. Roger (1998) sees inner emotional changes as integral to the spiritual journey. He comments that the essence of what is sought in physical form is actually inside us. We need to believe that success is within each one of us. Roger (1998) observed that endurance is built in the world through adversity: The triangulation of findings and literature suggests that we are strengthened through adversity, and how we handle the adversity is the critical measure of our growth. There was a sense that the adversity of disability reinforced the women’s spirituality of struggle that developed during apartheid (Kretzschmar, 1995; Tutu, 2004). The lived experience of the apartheid struggle meant that the women could relate to the hardships expressed in each other’s stories. The same sense of oppression, bias, inferiority and marginalisation was overcome. The symbols, as manifestations of the values of *Ubuntu*, are described in Part Two of this chapter.

Spirituality has often been seen as a source of healing and the renewal of energy for change (Hudson, 1995). Thus spirituality may be a means of restoring mental and emotional well-being, which was a persistent concern that was voiced by the women (Nouwen, 1976; Dyer, 2001; Fox, 1995). Whether we are disabled or not, a disability experience triggers will reshape our spirituality, as we rediscover our beliefs, values and rituals, faith, and the fruits of patience, tolerance, compassion and sharing. In a spirituality of disability, there is an intention related to the development of convictions, attitudes and actions that shape our lives, as it is given personal expression within daily living (Hudson, 1995:15; Roger, 1998). Dyer (2001) sees surrender and helplessness as part of spiritual growth, which is an integral part of the disability experience. The rich symbolism in their narratives and actions echoed the healing intentions of spirituality (Broodryk, 2002; Kretzschmar, 1995; Tutu, 2004). The symbolism appeared to dispel the silence of the oppression of disability discrimination that had been experienced at many different levels. Thus the sense of interdependence on one another was recognised in the giving and receiving support for personal growth and transformation, as encapsulated in the values of *Ubuntu* (Broodryk, 2002; Hudson, 1995; Tutu, 2004). The women regained a sense of self-dignity and renewed self-respect that fostered a collective identity, as they inspired each other to hope for success in development. Reason (1994:41) comments:

A person is a fundamental spiritual entity, a distinct presence in the world, who has the potential to be the cause of his or her own actions. To actualise this capacity and become fully a person is an achievement of education and self-development ... [the process] involves learning to integrate individualizing characteristics with a deeper communion with the others and the world.

Such connections occur as emotional resourcefulness is nurtured. Pain, hope and potential spoke to the essential qualities of love, courage and dignity that are encompassed in a spirituality of struggle, a spirituality of disability.

### ***Nurturing emotional resourcefulness***

A web of possibilities provides potential to nurture emotional resourcefulness, as the women drew on their spirituality to survive. The shared experience of disability revealed the interplay between emotional, spiritual and moral development. The study connected the women with the pain of their losses and the burden of disability. Emotional well-being and spirituality were seen as interwoven aspects in the human development of the women, as they developed a language to express their feelings and responses to disability. Shifts happened inwardly. They also developed emotional literacy as they engaged in meaningful occupations with others. The concept of “shared” highlights the difference compared to doing an inward journey of reflection individually or on a one-to-one basis. The stories strongly suggest that spirituality is core to human development, as Tutu (2004) comments that experiences of brokenness, vulnerability and fear are integral to human nature and suffering which we all experience at some time in our lives. For the women, these experiences were triggered following their impairment and subsequent disabling barriers. Acquiring impairments put the women in touch with their vulnerability and perceived loss of control and abilities. Working in impoverished rural communities had put me in touch with my own brokenness and vulnerability (Personal Journals, 1987; 1988). The spirit of *Ubuntu* seemed to provide a safe space where we were able to show our vulnerability. I found myself debating with the research facilitators about whether the experience of vulnerability should be seen as a weakness. In telling their stories, it was observed that humour was often a means of easing the pain and inspiring hope in each other as women experienced inner and outward change. We recognised the need for inner and outward healing. The sense of vulnerability raised a subsequent need for mutual support and reciprocity of family and neighbours. Where women have engaged in change inwardly, they created and rebuilt identities in spite of their disability (or rather integrated their disability into their self and collective identity). The shared inner journeys led to shared outward journeys into the families and community.

The moral-spiritual-emotional growth and awareness sharpened the women’s focus in accessing the necessary resources to increase their productivity in meeting needs. In many cases, women were providers as well as nurturers. Giddens (2001), writing about self-society relationships and social reflexivity in the late modern era, suggests that democracy cannot be limited to the public sphere. There is a potential ‘democracy of the emotions’ emerging in everyday life when societies engage with the imperatives of transformation. For example, in South Africa, the adoption of the new Constitution advanced the degree to which relationships within families; between employers and workers; between the State and the public; etc. are founded on mutual respect, communication and tolerance (Broodryk, 2002; Mbigi, 1995, 1997; Tutu, 2004). From a sense of self-reliance and inner strength, the women were able to rise above their worries and

anxieties and dream of a better life together. There was an intention to succeed in their endeavours. The women realised how they could use their time and energy more wisely and purposely. They challenged each other to change behaviours of self-pity and undermining their abilities, so as to increase their productivity. The changes echoed the characteristics of spiritual warriors (Roger 1998), which resembled the *Ubuntu* spirit of resilience (Tutu, 2004). The sense of interdependency drew together the pain, hope and potential of women in the study, as women gained confidence to participate in activities to foster human development as they found support from each other. The spirit of compassion in advocacy reflected the women's empathy for each other, as well as their neighbours. There were seldom feelings of superiority or inferiority towards others in the NAR workshops, but an appreciation of the trials that they all went through.

University of Cape Town



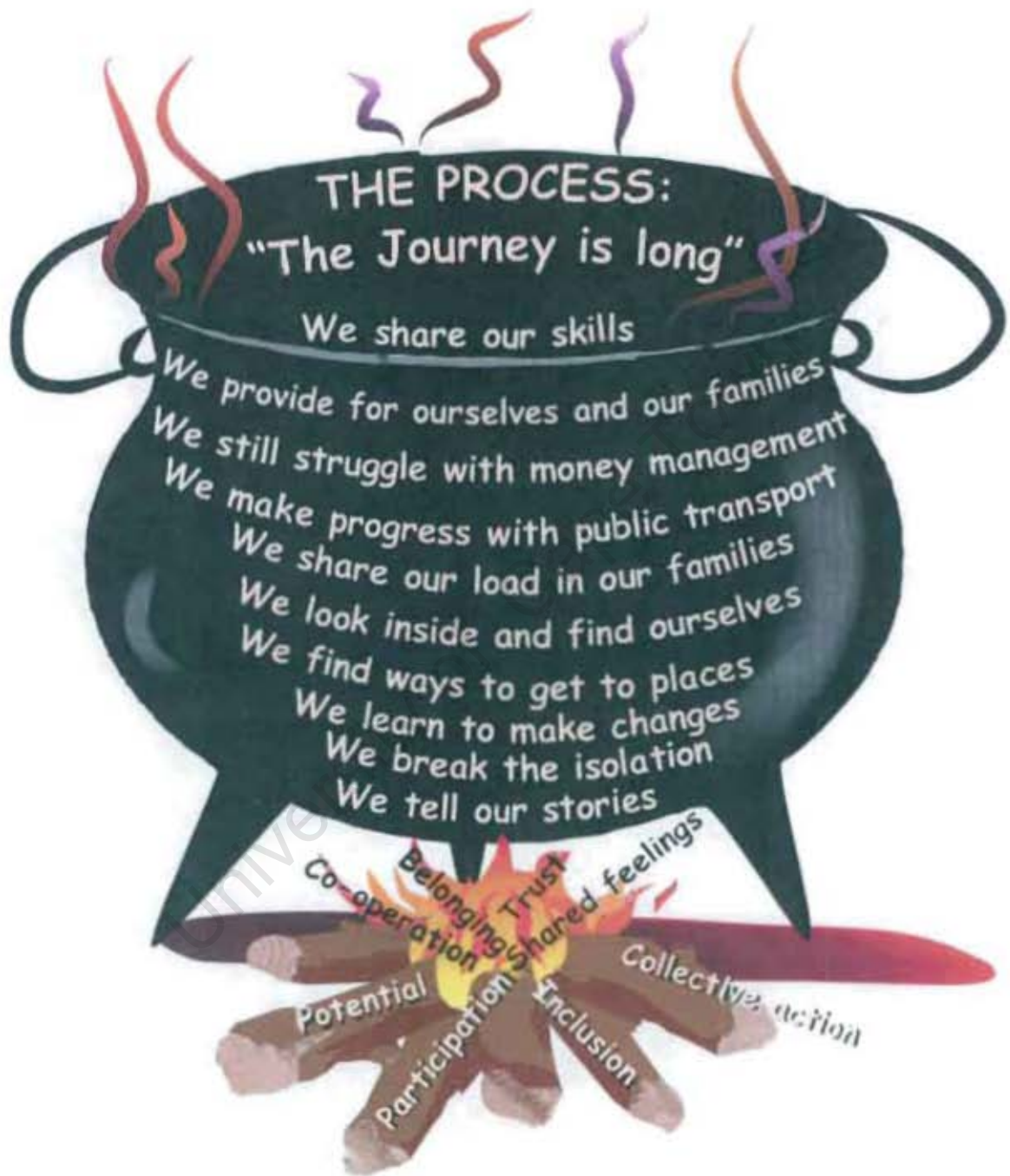


Figure 13.  
Narrative action research workshops as a method and a strategy

## NARRATIVE ACTION-REFLECTION WORKSHOPS: PIONEERING A NEW METHOD

In Chapter Four, I defined narrative action-reflection workshops as a combination of action-reflection and storytelling using creative activities to discover the meaning of human actions for social change. In the second part of this chapter, I turn attention to my second thesis, by triangulating evidence for NAR workshops as a relevant method for data generation that simultaneously provides a strategy for enabling social reflexivity (Giddens, 2001) and the emancipation of disabled people (Oliver, 1997). Baumann and Tester (2001:33) suggest that critical theory provides the opportunity to consider that “things are not necessarily what they seem to be... and the world can be different from what it is”. I propose that NAR workshops are a culturally sensitive method for emphasising the political aspects of knowledge production and for valuing the lived experience of disabled people in ways that advance their development and the fulfillment of their innate potential. Thus my second thesis argues for the adoption of a participative worldview that advocates the inclusive development of disabled people, as it recognises alternative ways of being attributed to human possibility, potential and experience (Bauman and Tester, 2001). A participative worldview “sees human beings as co-creating their reality through participation: through their experiences, their imagination and intuition, their thinking and their action (Heron 1992, cited in Reason 1998:262). The relevance of NAR workshops as a method for data generation and a strategy within research for the emancipation of disabled people will be expanded on now (see figure 13).

### Potential to generate data about collective experiences.

In reflecting on the NAR workshops as a method for data generation, the qualities proposed by Makgoba (1999) were recognised as relevant indicators to evaluate whether the NAR workshops contributed to a value-driven process that would build the capacity of the participants to engage in the African Renaissance. Each quality is explored below.

#### *A means of asserting and promoting humanity*

The NAR workshops confirmed that the starting point to change attitudes about disability should be disabled women themselves, which then have ripple effects in the family and the wider community. The NAR workshops provide the space for social reflexivity to occur, related to the beliefs and fears about being disabled, these workshops create safe spaces for exploring personal pain and loss associated with impairment.

NAR workshops promote active participation, which enables people to take more control over their own lives, as they make decisions on actions in the ordinary, daily household chores and community events. The interactions participants engage in lead to deep inner changes as they regain a renewed sense of identity,

dignity and respect from continued participation. The human needs of participation, freedom and rest (Max-Neef, 1991) are met both during and between workshops, as the participants realise the increasing range of choices that were available to them.

Another strength of NAR workshop was that the stories were shared as a collective, rather than on a one-to-one basis. It provides space for people to listen to each other's stories. Inner and outer journeys of action and change are generated and shared together. Change is experienced as dynamic and cyclical as it impacts on wider society in ripples. The use of creative activities reveals the richness of NAR workshops in promoting humanity as discussed later in this section. The NAR workshops provide a space where participants are able to share their emotions related to the depth of deprivation and discrimination. A quote from Bongiwe before Chapter One succinctly captured the depth of changes as a result of the process.

### *Readiness of participants to question themselves*

The workshops create opportunities for participants to shift from familiar, known roles of receivers of care to become catalysts of change. My second thesis is that these shifts need to be facilitated by enabling participants to reflect on their practice in a non-threatening, collaborative way, otherwise resistance to change is reinforced. Hudson (1995) comments that the dark emotions that are difficult to change are faced with resistance, which could then drain the facilitators and participants of energy. The facilitator's role becomes pivotal in helping participants to reflect on the root causes of problems and to identify relevant actions for social change in their everyday lives, even in small ways. Their role is to facilitate problem solving, planning and organisation to promote action-reflection between the NAR workshops, to enable participants to become catalysts of change. The facilitator needs to be able to understand the emotional undertones of groups and what members discuss informally. There needs to be sensitivity to the cultural norms of the group, although these may also be challenged in some instances. Facilitators need to heed the caution of Townsend (1995) who commented that marginalised people showed great faith in the power of the written word and the power of experts. They need to remain open to participants questioning them, and being accountable to the group in decision-making processes. In this way, a facilitator becomes a potential resource to relevant information and resources. Such changes reinforced the notion of empowerment through action-reflection – people can only empower themselves (Hope and Timmel, 1995; Christian, 2000).

### *Permanent openness of mind*

Action-reflection on the stories and experiences of participants promotes dialogue and participation in decision-making between the facilitators and participants. The facilitator's role is to alter and change the way that disability is perceived at an individual, family and community level. As the process unfolds, it may be necessary to balance the tensions of transformation (i.e. meaningful inward changes in the lives of the participants so that changes are sustained). The openness is also facilitated through creative activities, active listening and respect for each other's experiences. Telling our stories in a group means that participants may challenge each other's internal belief systems, values and convictions through dialogue and critical reflection to create a collective consciousness. The action-reflection process, promotes the building of social capital,

i.e. co-operation, commitment and collaboration, which enhance social harmony. Thus systems of mutual accountability to each other advocated by Flower and Wirz (2000) could be created in a way that generated encouragement and support.

The NAR workshops enable the identification of both individual and collective barriers. The process also enables the facilitators and participants to recognise the hidden potential for development in each person through a range of group facilitation methods that are utilised (Hope and Timmel, 1995; Roodt, 1995). Through the process of action-reflection, facilitators assist participants in formulating realistic plans to build confidence to challenge barriers that hinder social change. The action-reflection process in the NAR workshops takes pressure off the research facilitators who may sometimes feel that they have to have all the answers. At the same time, facilitators witness how action-reflection enables participants to make significant contributions to their development as they reflected on the actions they carried out after planning together.

#### ***A capacity for assimilation and adaptation***

It was mentioned earlier on that NAR workshops provide a channel for information sharing, accessing resources and finding out how to obtain much needed resources for business development and support. Needs for further skills or organisational development are identified through continuous reflection, which is beneficial in fostering the growth in self-confidence and hope. Changes occur as participants find the courage to take action to remove the many barriers and alleviate the human poverties. Such interventions would have a positive influence on the emotional health and well-being of both facilitators and participants.

There was a mutually strong message arising from NAR workshops for the research facilitators: recognise the value of continuing to foster and sustain the potential and passion for change and development that is ignited amongst participants in culturally relevant and sensitive ways. For example, in this study, as a faith-based health organisation, SACLA's vision was influenced and informed by Christian and African spiritual convictions and beliefs, which complimented the women's belief systems. These rituals had to be respected and given space in the workshop. Women prayed for healing for each other during some workshops. Participation in the workshops would also break the monotonous routine of fighting for survival, as the workshops are a space where participants would find some respite, support and nurturing of their spirituality. Likewise for others who experience marginalisation and other forms of oppression because of the vicious cycles of poverty and disability, NAR workshops provide some respite from the daily grind of poverty and discrimination.

#### ***A capacity for creativity and innovation***

NAR workshops involve taking risks and connecting with the power of personal beliefs through creativity and symbolism. Gueye's (1999) call for a restoration of self-confidence and the adoption of positive, creative attitudes towards our own history reinforces the relevance of NAR workshops as a research method that encompasses a strategy for change. An action-reflection approach to rebuilding the confidence and negotiation skills of disabled people would reinforce the move towards a better life, as it also facilitates the

growth in political development. To illustrate how the workshops enable capacity for creativity and innovation, I advocate that the symbols and cultural rituals used reinforce this aspect.

The women found engagement in activities within the workshops uplifting and inspiring. Their stories spoke of being candles, lights, lamps and stars that indicated the women's hope and potential to overcome their pain and isolation. These recurring symbols reveal how NAR workshops mirror participants' yearning to break through the darkness of despair and depression from disablement to shine again. The symbols become a source of strength that reveal the evangelical spirit that becomes a part of work. The workshops assist participants to overcome their sense of feeling powerless or poor. Thus there is space for emotional growth, and deep change occurs in the process.

The strength of reciprocity and solidarity to challenge discriminatory and harmful attitudes was clearly evident in the clay sculptures that were made to depict the changes participants experienced. The sculptures and drawings reveal the richness and depth of cultural norms and values. The sculptures also depict the move from dependency to interdependency and changes that participants regard as meaningful. Creativity involves purposeful interactions that may strengthen a sense of interdependence. A deep concern for the growth in well-being develops among the participants. The importance given to faith in God or a Higher Being as a source of energy, strength and provision, a source of hope was significant. This faith was seen in the common symbol of trees, seeds and plants representing growth. A planted tree was another symbol used to depict their potential for growth, rooted in their faith and belief in God's ability to provide for their needs.

It is clear that creative activities provide solitude and silence for personal reflection as well as sharing thoughts and feelings. Hudson (1995) comments that a safe, spacious and sacred space for self-disclosure and honest communication is essential. Such spaces were provided through creative activities during the NAR workshops. The workshops allow time for personal testimonies, prayers and dancing, singing songs of struggle and hymns of praise. Spontaneity is engendered in different ways, such as when a woman sings a praise song to the co-facilitator on different occasions. This action signifies the appreciation and respect one person has for the other, and is a way of honouring her/him (Broodryk, 2002). In this way, NAR workshops produce benefits and outcomes during the process and not only at the end, despite the absence of sufficient material resources. It equalises the power that is often manifest in the differences of educational levels and literacy skills. We need to value the richness and depth of human resources and potential. The workshops enable change through participation in opportunities for storytelling, skills development, engagement in everyday activities and social integration.

#### ***A spirit of rigour, organisation and method***

The structure of the workshops allows the facilitators to address the human needs and opportunities amongst the women systematically, yet with flexibility. We could identify with Chambers' (1995:41) assertion: "Participation which truly empowers implies a process which is unpredictable". It is in this light that the traps and problems in participation raised by Chambers (1995) are pertinent in considering the relevance of NAR



workshops as a research method. In looking at who participates, he maintained that the poorest are often missed. He claimed that practitioners are usually in a hurry and fail to facilitate an on-going process that ensures the inclusion of the poorest. NAR workshops enable the facilitators to resolve the power dynamic of inclusion/exclusion. The action-reflection process, in NAR workshops, help identify potential traps or defences against change that may occur. Through reflection on actions, the participants and facilitators became vigilant of potential traps to authentic participation in human development.

Nelson and Wright (1995) referred to Lane who pointed out that participation is always risky because it will challenge local power structures. The PAR study becomes part of a developmental process that includes education and political action. Self-reflection and a deeper understanding of the research situation by the participants is nurtured through NAR workshops. The process leads to a shift in power relations and dynamics. The active participation in the groups fosters the growth of personal ideals and aspirations to better their situation and gives a sense of personal power. The action learning groups that should occur between the NAR workshops supported Coleridge's (1993) challenge for social action to change the attitudes and approaches to disability from the constant focus on rehabilitation that perpetuates the idea that disabled people must be normalised, taken care of, and treated as perpetual patients.

#### ***Combine emotion and reason in our response to development***

NAR workshops create a means for open exploration of inner and outer emotional changes, as described in Part One of this chapter. The building of emotional resourcefulness of individuals and groups has been recognised as an important goal of development processes (CDRA, 1999; 2000). The process in NAR workshops suggests that emotional resourcefulness needs to be addressed more consciously in human development and planning. The ripple effects of emotional nurturance that enabled change at an individual and collective level were profound. As research facilitators, we discussed amongst ourselves the nature of the changes in the inner emotional resources needed for facing the challenges of poverty alleviation and development. We learnt the value placing trust in the group's potential and ability to succeed, as it encourages sharing the outcomes of actions. NAR workshops seem to foster the potential of participants to move beyond survival. Facilitators need to balance the tension between task and maintenance roles (Hope and Timmel, 1995). So it was both a matter of getting the tasks and activities completed, as well as, the group dynamic and building a web of reciprocal relationships to develop a network for collaboration and collective action, that then present a web of possibilities for development.

The NAR workshops generate opportunities to address the different aspects of development, namely, political, social and economic, simultaneously with the spiritual, emotional and moral development (personal growth) (Tutu, 2004). Facilitators could become catalysts for change through action-reflection. At a personal level, I became aware of the continuum of emotions I experienced ranging from excitement and exaltation to frustration and exhaustion, often related to my perception of the slow pace of change. The impact of meeting together on a regular basis provides an opportunity to share fears and anxieties openly. The cycle of change (Foster, 1993, 1996, personal communications) gave me confidence, as I understood that the root emotion of



fear usually precedes the participants' responses of anxiety or excitement. It is essential to support participants by responding with excitement and help manage the initial uncertainty related to the risk and struggle of change. The outcome is growth. If anxiety is too high, defence mechanisms of pairing or flight/fight, withdrawal and willing ignorance are adopted. The result is stagnation and 'death'. The relevance of action-reflection cycles in breaking the impasse is significant. Through exploring fears and anxieties the participants are able to move beyond stagnation to goal-directed action that contributes to personal transformation and social change (Lorenzo, 2003; Lorenzo, 2004).

### **Was there emancipation through participation?**

*I've changed a lot. This lamp must remain on top of the table. I wish that other people who were not here can learn a lot from us and we can share with them. (Angela's voice, Aug 2000)*

Since working with the disabled women, I realised that teamwork is very important... At the beginning we fought and were angry with each other at times, but we were also able to laugh and have fun. We thought we had to go in and do things for them. Often as a professional we can get stuck on seeing the problems and the struggles... We have become a family... But it takes time; it's a long-term commitment to build our own capacity as well as the capacity of each other. (Facilitators' voices) (Lorenzo *et al.*, 2002:43-44)

For me this has been a challenge and a long journey... When I met with the women, I was thinking, "Oh my God, how am I going to cope?" I didn't know where to start. (Facilitator's voice) (Lorenzo *et.al*, 2002:44)

This question raised by Oliver (1997) about disability research stayed with me throughout the study and became a yardstick for my decision-making. It is answered succinctly in the quote above. Oliver stated that researchers are not able to determine whether the research will be emancipatory until it is implemented. His key principles of reciprocity, gain and empowerment to measure whether research with the women led to their liberation were used as yardsticks to account for meaningful change as recognised by the women. NAR workshops allowed us to achieve these benchmarks, as seen in the accounts of the stories of change by the women and facilitators.

The workshops allowed the research facilitators to produce a collective account of collective experiences through the workshops, rather than individual interviews of collective experiences or one-on-one accounts. Telling stories was familiar to the cultural ethos of the women who participated than individual interviews. Collecting the data from women as a group enriched the experience for everyone, as it reinforced reciprocity. Although it was intended to look in more depth at the attitudes of health professionals and service providers generally as they impact on the health of families (especially their mental health), this did not happen. It may also have been that there were more women who felt strongly about the attitudes of taxi drivers, as accessible public transport was seen as a major barrier to sustainable livelihoods.

The experience of doing PAR with the disabled women meant that there were opportunities to tackle the power dynamics and tensions related to differences and diversity. The research process was emotionally laden, because it challenged everyone's passivity, stereotypes and experiences of oppression. We found that often a reaction to something said 'innocently' triggered painful memories or feelings of mistrust for others. As a group we had to learn to allow time for addressing the underlying dynamics and interpersonal difficulties by creating a space where the women, CRWs or research facilitators were able to share their conflict. The tensions and feelings were sometimes difficult to contain, which provided opportunities for learning conflict management skills.

The process of developing group cohesion was often slow and frustrating. At times it seemed as if change was impossible, as little progress was made. It felt that we kept on experiencing the same interpersonal and logistical obstacles. There was mutual frustration as the research facilitators attempted to get women to identify actions they would take and the women's expectations were that we, as the facilitators or the CRWs should be solving the problems for them. As facilitators, we were not interested in just expanding and enlarging the number of women who engaged in development projects. We hoped that the PAR process would alter and change the way that disability was perceived at an individual, family and community level. As the process unfolded, we had to *balance the tensions* between development, which usually means increasing the number of women who access skills development opportunities, and transformation as meaningful inward changes in the lives of the women so that their initiatives succeeded and were sustained. Linked with this was the need to improve communication and co-ordination, as part of the capacity of SACLA Rehabilitation Project, DPSA and UCT to work in authentic partnership. Action-learning enabled all of us to understand the movement from dependence toward self-empowerment. Kaplan's three phases of development from dependency to interdependency provided a useful framework for recognising and confronting defences (Kaplan, 1996). A frequently used defence against the anxiety associated with change was blaming between the CRWs and the women who claimed not to get information on time. It was "somebody else's" fault that they didn't come to the workshop instead of taking responsibility themselves. Dependency on "someone else" to do everything also served to defend against the women's anxiety against owning the locus of control for personal development. If something did not work out as expected, the women would go to another CRW or research facilitator rather than resolving the tension with the first person. Confrontation involved bringing the dynamics of avoidance behaviour to conscious awareness and facilitating ownership of responsibility for self-empowerment (Roodt, 1995). It was all too easy to blame underdevelopment on factors external to oneself rather than taking the responsibility for changing the situation. Often, emotions were revealed in other contexts as well.

As the only person in the group who could not understand or speak Xhosa fluently, I was at an obvious disadvantage. Being the minority and "different", I had a simulated experience of exclusion at times. While Marjorie and Peliwe were competent in facilitating the workshops and managing all stages of the research process, it was frustrating not being able to engage actively during the workshops, and having to wait to get

clarity or deeper understanding. I also missed out on the informal conversations and joking, which is difficult to translate in the moment, as the meanings get lost. It made me aware of how difficult it is to let go of control, because one feels redundant. It was also difficult to keep consistent records of the process and change, as I often felt driven to action, and questioned the value of the research, which seemed to be too time-consuming. Listening to the women revealed the hidden hardships related to the nature and size of the workload and the multiple responsibilities that they routinely carried. I often needed reassurance from supervisors that in being present and creating space for the women to voice their experience, I was 'doing' something meaningful and beneficial to them. At times I lost faith in the women's situations changing for the better, and did not have confidence in my abilities to manage the process. The anxiety and stress was evident in the tensions and arguments that occurred with Peliwe or the CRWs for "not doing something". Marjorie often mediated these tensions.

It has already been mentioned that we were often overwhelmed by the extent of the barriers and the extreme situations of poverty and discrimination that the women endured. While the action-learning approach facilitates pro-activeness, it was hard not to feel demoralised and pessimistic about any significant long-term change happening for the women. At times, the situation did feel hopeless, and we at least had some reprieve from it as we 'moved in and out'. The burden of women's expectations and hope that we would be able to alleviate their suffering in any small way was heavy to bear. I came to appreciate how the singing, dancing and testimonies reflected the deep spirituality of the women, which saw them overcome the evil of apartheid, and that kept me humble and hopeful! By embracing their pain, inspiring hope for a better future and operationalising innate potential we felt liberated to act individually and collectively in claiming our rights to inclusion.

When we choose to see situations as opportunities, when we look within for answers and guidance, we find our outer world reflects our inner conditions. As we become more gentle and harmonious so do our outer worlds. As we become more adventurous and expansive, so do our worlds. We are co-creators not victims of circumstances! (Bryan and Cameron, 1998) (Journal Entry, 2 June 2000)

At the writing up stage, the approach was open to the criticism of reinforcing isolation and individualism as I did the bulk of the write up as the primary researcher. However, the process of consultative dialogues ensured that the women's voice was represented as accurately as possible. Feedback sessions for purposes of member-checking were lead by the Xhosa-speaking research facilitators. The research assistant also interacted with the women in meeting with groups between the workshops. Thus the women had opportunities to raise questions of concerns, which they found empowering.

## REFLECTIVE SUMMARY

During the study, the opportunities to learn and appreciate the meaning of African customs in integrating disability into development practice and research emerged. I approach this task of thesis building with humility as a white person discovering the richness of my African inheritance, and with full acknowledgement that I still have much to learn, understand and change about myself in relation to others. In this chapter, I have presented my thesis, which is twofold, but interlinked: an *Ubuntu* approach to disability will foster interdependency in interactions, and will promote social harmony. Disability enkindles an innate spirituality that becomes a source of power through the narrative on individual and collective experiences of disability. The spirituality of people has been dormant in human development discourse and projects, which have largely excluded disabled people. These experiences suggest that interdependency and a spirituality of disability need to be a driving force or catalyst to achieve equal opportunities in human development for disabled women. These changes would mean that the women experience improved access to health services, public transport, and other social systems. Their appreciation of interdependence and spirituality provided a source of energy needed to sustain the process of inclusion and social change.

The second part of the thesis building sought to validate narrative action-reflection workshops, as a relevant method for participatory action research in disability and human development, as well as a potential catalyst for change and empowerment. NAR workshops provide the method for this to occur. The last chapter presents suggestions for further action and research.

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## Chapter 8

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# On the Road of Hope: Suggestions for Further Action

### Introduction

### Suggestions

**Signpost 1: Redraw images of disability Identity**

**Signpost 2: Recreate strong family and community networks for social harmony**

**Signpost 3: Retraining stakeholders to facilitate equal opportunities**

**Signpost 4: Advocating a public health approach to disability**

**Signpost 5: Lobbying for accessibility of transport and information as a precondition for equal opportunities**

**Signpost 6: From food security to sustainable livelihoods and beyond**

**Signpost 7: Exploring other impairments**





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# On the Road of Hope: Suggestions for Further Action

### INTRODUCTION

The nature of participatory action research is such that I have decided not to draw conclusions (Price and Kuipers, 2000). Rather, I have tried to integrate the findings and dialogues to indicate plans for further action. The stories of women in equalising opportunities have been illustrated in the preceding chapters. Chapter Eight suggests seven signposts for further action and reflection to reinforce and, hopefully, further the outcomes of this study.

#### **Signpost 1 Redraw Images of disability identity**

The current study described the nature of the identity of women since being disabled. The findings revealed the importance of reshaping disability identity by integrating our fears and insecurities through the use of imaginative and creative techniques as a non-threatening way to get some resolution. During the study, I recorded that identifying and utilising individual and collective capacity is hard work that demands emotional resilience of both the participants and the research facilitators (Journal Entry, 25 July 2000). We all have different levels of understanding, which meant that, as catalysts for change we have to be aware of our shadows to be able to facilitate and mentor effectively (Journal Entry, 9 August 2000).

A further study to explore the commonalities and differences between disabled and non-disabled women in this community in more depth could potentially further inclusion in human development. It has been shown that the women have similar experiences to non-disabled women. Therefore, systems could be put in place to address the problems of poverty alleviation that would be inclusive of ALL people. Further research on the identities of disabled women who are not poor, as well as poor non-disabled women to understand the many interfaces and intersections of diversity, which has been beyond the focus of this PAR study, is indicated. Vernon and Swain (2002:83) comment:

The experience of disablism, racism and sexism may be modified or exacerbated by the presence of privileges or other penalties respectively.

While the current research focused on women, further research to explore the nature of human development of disabled men would identify similarities and differences in experiences related to barriers and strategies, so as to reinforce inclusion.

Parents of disabled children and disabled children themselves should also be given opportunities to share their experiences.

## **Signpost 2 Recreate strong family and community networks for social harmony**

### ***At a family level***

Families were recognised as an important source of reciprocal support that needed nurturance as they learnt to manage many transitions linked to their impairment. Given the prevalence of domestic violence that was experienced, it is surprising that the women never spoke of the changes in their families regarding the relationships with their siblings, partners or husbands. They did not give any account of the impact of their increased confidence on these primary relationships, and if there was any difference in the frequency of domestic violence. Thus it is an area that warrants further research, as it has not been given sufficient attention here.

Parenting and childminding appeared to be a common social burden and tension, while at the same time giving the women a worthwhile occupation that contributes to their sense of identity. A dynamic that needs to be further researched is the impact of disability on siblings or other children in the family context.

### ***At a community level***

The successful formation of a partnership between disabled peoples organisations and service providers is dependent on building the capacity for self-reflection, trustworthiness, mutual accountability, reciprocity, shifts in power relations towards shared responsibility, guided action and an ability to show feelings of vulnerability by all role-players. The role of strong social networks would be worthwhile to research in-depth as participation was shown to be essential to overcome human poverties and disability discrimination. The nature of different participatory approaches and action-learning in community development initiatives need to be documented and disseminated widely to facilitate policy implementation and influence training of public health professionals.

It is thus imperative that health care professionals are trained in the changing approaches and theories of disability so that relevant services are delivered. These experiences highlight the importance of practitioners responding to the existing capacity that women demonstrated for effecting change to reinforce and strengthen their efforts.

A woman's health and well-being may be unnecessarily comprised by lack of access to services, inaccessible medical equipment, inadequate public transportation and lack of disability-related training among health care and other service providers (Nosek *et al.*, 2003:1738).

The concept of interdependence of *Ubuntu* to foster reciprocal forms of support may be worth investigating in-depth to improve service delivery and determine the nature of local resources that contribute to sustained development efforts by the women.

### **Signpost 3 Retraining stakeholders to facilitate equal opportunities**

The opportunity for telling their story was a powerful tool in breaking the social isolation that most women experienced following their impairment. The complexities of disability (see Figure 8) were clearly illustrated in the different experiences of the women. The strength and value of sharing compassion by being vulnerable while at the same time engaging in action-learning was evident in the changes that occurred. In training future health practitioners, the danger of ignoring parental skills, expertise and concerns because of the power differences needs to be highlighted. Read (2000:64) identified that mothers of disabled children saw professionals as the gatekeepers to resources because:

[They] may have the power to operationalise policy at the face-to-face level, their assessments and informal opinions may influence the allocation of resources, their definitions of problems and needs as well as people carry weight and they can impart or withhold information in ways that make a difference to children and their parents.

The women have shown that the vicious cycles of poverty and disability can be broken by the concerted efforts of all stakeholders. Stories are a valuable way of personal growth and self-discovery (Hudson, 1995; Villa-Vicencio, 1995). Aspects related to human rights and human poverties were uncovered. Thus social justice through transformation was deemed an essential goal to strive for with the women. Further research focused on the training of disabled people's organisations, practitioners in public health services and researchers from other communities in the method of NAR workshops could determine the feasibility of the method for data generation, as well as a strategy to equalise opportunities to achieve social transformation and justice. I propose that rehabilitation therapists could implement NAR workshops to facilitate the transition from hospital to community, so that disabled people have an opportunity to receive support from each other and their facilitators.

### **Signpost 4 Advocating a public health approach to disability**

The stories reflected the vulnerabilities experienced by the women, which included road traffic accidents, substance abuse, domestic violence, housing and access to health and social services. These aspects are public health issues. It seems that practitioners need to be made more aware and sensitive to this responsibility that women bear (Hartley *et al.*, 2002). Many writers have emphasised the considerable lengths women and mothers go to to create safe spaces for their children to remain healthy and grow emotionally and physically. Ironically, they suffered most from the lack of a safe space for themselves from the violence and trauma, which often exacerbated the impairment effects. The women spoke of burnout due

to exhaustion from the multiple forms of exploitation. The practice of putting the needs and health of family members first is not unlike other mothers (Doyal, 1995; 2003; Read 2000). The women assumed the responsibility for the health of other family members at a serious cost to their personal ability to succeed in development. The PAR study was a dynamic and interactive process of change that impacted on my teaching, as well as getting disability on the public health agenda concurrently with data production. In the light of scarce resources for health and human development, practitioners in public health services need to be instrumental in research and policy development processes to address the multiple experiences of disability discrimination that women face.

I am often struck by the sense of struggle that many practitioners seemed to experience with changing to or adopting a human rights approach to disability. The stories provided evidence that practitioners need to be able to manage the tensions and emotions evoked in the transitions that are triggered by impairment of the individuals and the ripple effects on family members and the wider community, as identities are fluid and dynamic. The PAR showed how CRWs became an important buffer, as they accessed information and other support systems to benefit the women's development. These experiences need to be more diligently and rigorously documented to provide evidence for the recognition of CRWs as essential health resources and partnerships for improved service delivery (Hartley, 2002; Finkelflugel, 2004; Wirz, 2000). Thus health and social services need to learn to work in partnerships with diverse stakeholders for mutual benefit and co-operation, in order to increase access to resources and information, showing respect for power. Participation is affected by language differences, which can be meaningfully addressed through partnerships that would bring in different competencies of stakeholders. We need to develop common goals so that more is achieved.

In addition, the interdependence of self and collective identity in human development has been identified as a new area of knowledge that has implications for service delivery. Practitioners working in the disability field need to re-look at the goal of independence in rehabilitation process in the light of the philosophy and values of *Ubuntu* identified in the changes voiced by the women. It is this interdependence in meeting personal, emotional, and spiritual needs that the women have spoken of so strongly as the means to social, political and economic development. This is not only for themselves as individuals but for their families as well. It is imperative that all practitioners manage the interactions with all disabled people, men, women, youth and children, in a constructive and enabling manner through building friendships first. Research into the integration of the cultural influences and value systems into the rehabilitation of women, together with their families, is recommended (Coleridge, 1999b).

### **Signpost 5 Lobbying for accessibility to transport and information as preconditions for equal opportunities**

Universal access, especially public transport, the built environment and information dissemination were found to be the weak links in ensuring sustainability of initiatives to ensure participation in target areas identified in the UN 22 Standard Rules (UN, 1994). For the women to benefit from and be involved in raising awareness on

disability as well as accessing health and rehabilitation services, access to transport was seen as essential. The study, therefore, proposes that transport and information (*Standard Rule 5: accessibility*) be considered as a precondition for participation rather than one of the target areas as it currently stands. Research into strategies to build the capacity of women to tackle accessibility barriers is indicated. Information and documentation need to be more readily available in a format accessible to women who have low literacy skills. The proposed basic income grants needs to be dually considered by government as an essential resource for human development and equal opportunities for disabled people. Their struggle with local councillors in trying to secure land for building a place to work indicates that awareness-raising and dissemination of information related to disability issues at local government level is essential, and needs to be supported.

The developmental impact of the proposed spatial development strategies in areas such as Khayelitsha will be significant, not only in the economic opportunities that they generate, but also in the overall improvements that they will make to people's quality of life, and levels of accessibility through enhancing the local socio-economic infrastructure (Dyantyi and Frater, 2004). Research needs to monitor how effectively information is disseminated to disabled people, and women specifically, so that they are integrated into these critical initiatives.

## **Signpost 6 From food security to sustainable livelihoods and beyond**

The findings provide ample evidence of how the women optimised their grants for overcoming human poverties simultaneously. Thus there is strong evidence for lobbying policymakers at national and international level that *Standard Rule 8* on Social Security and Income Maintenance of the Standard Rules (UN, 1994), which is currently identified as a target area for participation, should become a precondition for equal opportunities. The basis for the motivation is supported by evidence of how disability grants were used as seed money for income generation initiatives, which then provided resources to enable participation in other target areas such as education (*Standard Rule 6*), family life (*Standard Rule 9*) and culture (*Standard Rule 10*). Evidence of the value of social security and income for enabling a provider role necessitates that the policy of re-evaluations of disability grants needs to be rigorously debated for policy purposes. It placed tremendous stress and burdens on the women and their families since DGs were often the sole income in many families.

The research facilitators debated with the staff of SACLA Rehabilitation Project about whether giving food parcels from the Departments of Health and Social Development by various organisations including SACLA, exacerbated dependency instead of facilitating human development in some cases. Food parcels may be a short term solution for destitute families who have no means of survival other than neighbours' generosity. Such provision needs to be matched by skills development for longer-term sustainability. It raises the challenge related to how CRWs, as well as public health and development practitioners, use action-learning to create a shift in the women's perceptions regarding food parcels where the women see their own potential for development. CBR needs to be seen as more than service provision, but rather a strategy for poverty



alleviation and supporting sustainable livelihoods (Lorenzo *et al.* 2002; Lorenzo, 2003). To achieve this, we need to continue studies such as these and ensure that findings are disseminated and published widely.

Resource management has been recognised as an essential element in the sustainability of self-directed employment and entrepreneurship initiatives (Neufeld, 1995; Campos, 1995). The action stories revealed an essential challenge to practitioners of how to establish effective financial management systems for groups in impoverished communities where there is a low level of literacy and numeracy skills, but a high degree of agency and aspirations to succeed. Financial literacy was found to be a key strategy that the women needed if their groups were to become economically empowered, independent and self-sustainable (Taylor *et al.*, 1998). Was this a realistic goal for women in impoverished communities? Work with development NGOs to provide literacy training as well as business skills development including financial literacy was identified as crucial. But financial literacy needs ongoing coaching and mentoring to ensure sustainability through effective project management and organisational development. Thus resource management as a critical issue of sustainability of business initiatives should be the focus of further research.

Stories illustrated that many women were constrained by low levels of education and illiteracy, as identified in Chapters Five and Six. As a consequence, the self-employment initiatives that they were involved in were low-income jobs. Women need to be exposed to other possibilities that are viable and generate greater income. It also became evident that there was a need to link the women to learnerships<sup>25</sup> in Departments such as Tourism and Arts and Culture, which would contribute to strengthen existing strategies of women. NGOs and DPOs need to be more proactive in negotiating for learnerships and other skills development programmes through the Sector Education Training Authorities (SETAs) under the South African Qualification Authority of the National Qualification Framework. The action stories have indicated that the women have potential to become more actively involved in ventures as part of the Black Economic Empowerment. Thus there is a role to carry out collective case studies to monitor and document the outcome of these initiatives, so as to identify strategies for success in human development that leads to long-term employment.

## **Signpost 7 Exploring other impairments**

The study did not focus on ensuring representation of the various impairment groups in the sample, as snowballing was used. As such it may be criticised by some for not covering the needs of people with primary psychiatric impairments, and people with profound hearing and communication impairments. One reason may be that SACLA has not worked with many women with psychiatric or hearing impairments (Hartley and Wirz, 2000). This may be due to the fact that the training of CRWs did not cover these impairments in depth. It does not indicate that there are no deaf women or women with psychiatric impairments in the study area. It could be argued that in a social model approach to disability, the needs and barriers to integration and equal opportunities

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<sup>25</sup> Learnerships have been created through the Skills Development Act (2000) that requires all institutions to pay a skills development levy. Sector Education Training Authorities have been Established by the national Department of Labour in the different sectors. Each sector should have an equity plan, which should address needs of disabled people.

may be similar at a societal level. Specific needs related to the impairment would have to be identified through snowballing to identify individuals with these impairments and explore their ability to participate. Doing collaborative research with organisations such as Cape Mental Health and DEAFSA would also provide evidence of the experiences of people with psychiatric impairments and communication impairments. It is recommended that this be studied further, using a sign language interpreter as part of the research team.

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# Epilogue

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## PLANTING SEEDS

Reporting on the study with the disabled women began with my story. It seems fitting to end with a mention of some the transformation I experienced. The experience was filled with many meaningful interactions: there were frustrations, disagreements, arguments, and worries. But there was much more singing, dancing, laughter, encouragement and support, as we shared our difficulties and found ways to tackle them together. We had opportunities to celebrate the changes that we witnessed. The PAR study has changed my life and practice irrevocably, at both a personal and professional level.

### Mutual learning

I am an even stronger advocate for the power of storytelling and action-learning. The narrative action-reflection workshops provided a means by which I was able to connect with the interdependency of each of us and learn from the spirituality of the women. It also meant that it was not necessary to have all the answers to development for the women. The workshops assisted the women in identifying their individual and collective barriers and to act to change these. I was always conscious of the power dynamics amongst the facilitators, with differences in language, education and experience. My role grew into one of planting seeds in the form of ideas or challenges and watching the women respond and grow. I continually encouraged the co-facilitators to lead the workshops. It was fortuitous that I had three months study leave during the six-month period that focused on skills development. While I was in contact with them via email or telephone, it was an opportunity for them to take full responsibility and control. Women continued to participate actively in the workshops, which was affirmed by the two facilitators. Workshops were no longer dependent on the 'mlungu' [white person] being present. A new sense of ownership seemed to emerge in the group. The CRW co-ordinator voiced the sense of achievement in the group:

*This workshop is great. Even though Theresa is not around, women didn't choose and say we won't participate because she's not around. The women participated very well.*

### Bearing fruit

Anyone who has worked with in the development and disability fields will know that you cannot avoid being deeply challenged in your values, biases and stigmas or left unchanged. Such has been my experience through

practice, teaching and research, especially during this study. I have been enriched by the diversity of experiences. I have been humbled by the generosity of people living in abject (material) poverty. I have often felt that I have learnt and benefited more than the women I was supposedly helping. Tom Shakespeare (2000) raised this question about the relationship between “the helped” and “the helper”. I learnt that being present to the women through listening to their story was as important and meaningful as ‘doing’ a task. Often I found myself worrying about whether the women were benefiting from their participation. In a midway peer evaluation, my co-facilitators encouraged me to trust the process and have confidence in the women and myself. It was difficult to be consistent in recording our reflexive thoughts and ideas as facilitators, as we were all multi-tasking, not unlike the disabled women. The consultative dialogues helped us to maintain the momentum as well as support each other, aware that: “If we can’t express the things we are learning from people, then we’ll never get anywhere” (Lipson, 1994:279).

### Facing our vulnerability

Many people experience the disability field as rife with emotional landmines (Haricharan, 2002; Lorenzo *et al.*, in press). It is probably related to the fact that we face our own vulnerability and fears in interactions with disabled people (Watermeyer, 2000). Our fragility is exposed. As the women in the study expressed, anyone could sustained an impairment, at anytime. It is something we have little, if any, control over. I came to appreciate just what women were coping with and their creativity in the struggle to survive, which led me to explore a spirituality of disability. They have experienced and coped with immense emotional turmoil, resulting in significant growth and development. The meaning and purpose that they have drawn from their experience made me re-appraise the assumptions and views I held about the lifestyles of disabled people, generally, and women, specifically. As practitioners, academics and researchers, we need to begin to integrate disability issues into all aspects of our work. Disability is an equally important area of diversity and difference where there needs to be equity. We are challenged to share our vulnerabilities and not to hide behind our professional boundaries. We need to extend our boundaries to create an inclusive practice of teaching, research and service. Max-Neef’s approach of Human Scale Development made me realise the areas of human poverty that I experience, even though I had had many privileges and opportunities as a middle-class white person, which were denied to the majority of South Africans. Many of these poverties were met through interactions in different contexts! I really felt like I belonged in the group for who I am. I have appreciated the essential nature of non-material richness. I think that HSD and action-learning are essential strategies for poverty alleviation and disability equity.

In March 2002, SACLA merged with two other primary health care NGOs to form Zanempilo Health Trust. Sadly, at the end of 2002, all staff were retrenched, due to financial constraints. The CRWs have continued to work on voluntary basis, which has lead to having to reduce the hours given to the project.

## Majorie

Teaching, service and research are seen as the pillars of the academic life (UCT, 1996). UCT aspires to be a world class African University. As such the University is challenged to engaged in disability as an issue of diversity and equity to ensure that teaching and research integrate disability in all spheres of its activities. The partnership with DPSA extended to include negotiations on the development of a postgraduate programme in Disability Studies<sup>26</sup>. Acknowledgement and appreciation of the quiet, yet strong, diplomatic and mediatory role that Marjorie played needs to be noted. She was able to bridge the gap between an academic institution and the Disability Rights Movement, as she recognised the benefits for both sides. Sadly, Marjorie passed away in December 2004. As a small symbol of appreciation for the important role she played in the research and the partnership with DPSA, I dedicate this PhD to her.

In closing, I echo Marjorie's words:

*If we can do this again, we will do it with others!*



Marjorie (left) in dialogue with a woman

<sup>26</sup> Those interested in its developments are referred to Lorenzo, *et al.*, (in press).

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# References

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- Abberley, P. (1992) Counting us out: a discussion of the OPCS disability surveys. *Disability, handicap and Society* 7, (2) 139-156.
- Abrahams, N., Jewkes, R. and Laubscher, R. (1999) "I do not believe in democracy in the home": Men's relationships with and abuse of women. CERSA (Women's health) Medical Research Council, Tygerburg, August
- Abu-Habib, L. (1997) *Gender and disability: Women's experiences in the Middle East*. UK and Ireland: Oxfam.
- Asindua, S. (2002) What is CBR in an African context. In *CBR: A participatory strategy in Africa* (edited by S.Hartley) London: University College London, Centre for International Child Health. 26-36.
- Bailey, D.M. (1997) *Research for the health professional: a practical guide*. Second edition. Philadelphia: F.A. Davis Company.
- Barberton, C. (1998) Obstacles to effective participation by poor people. In *Creating action space: The challenge poverty and democracy in South Africa* (edited by C. Barberton, M. Blake, and H. Kotze) Cape Town: David Philip Publishers. 244-271.
- Barberton, C. (1998a) Introduction. In *Creating action space: The challenge poverty and democracy in South Africa* (edited by C. Barberton, M. Blake, and H. Kotze) Cape Town: David Philip Publishers. 3-10.
- Barberton, C., Blake, M. and Kotze, H. (eds) (1998) *Creating action space: The challenge poverty and democracy in South Africa*. Cape Town: David Philip Publishers.
- Barnes, C. (1992) Qualitative research: valuable or irrelevant? *Disability, Handicap and Society* 7, (2) 115-123.
- Barnes, C. (1996) Disability and the myth of the independent researcher. *Disability and Society* 11, (1) 107-110.
- Barnes, C. and Mercer, G. (eds) (1997) *Doing Disability Research*. Leeds: The Disability Press.
- Barnes, C., Oliver, M., and Barton, L. (2002) Introduction. In *Disability Studies Today* (edited by C.Barnes, M. Oliver, and L. Barton) Cambridge: Polity Press. 1-17.
- Barnes, C. and Mercer, G. (eds) (2004) *Implementing the social model of disability: Theory and research* Leeds: The Disability Press.
- Barron, K. (1997) The bumpy road to womanhood. *Disability and Society*. 12, (2) 223-239.
- Barton, L. and Oliver, M. (eds) (1997) *Disability Studies: Past, Present and Future* Leeds: Disability Press.
- Bauman, Z., and Tester, K. (2001) *Conversations with Zygmunt Bauman*. Cambridge: Polity.
- Benn, C. (1998) *Madonna and child: Towards a new politics of motherhood*. London: Jonathan Cape.
- Beresford, B. (1994) *Positively parents: caring for a severely disabled child*. London: HMSO.



- Beresford, B. (1995) *Expert opinions: A national survey of parents caring for a severely disabled child*. Bristol: The Policy Press, in association with the Joseph Rowntree Foundation and Community Care.
- Begum (1990) *The Burden of gratitude: women with disabilities receiving personal care*. University of Warwick: Social Care Practice Centre/Department of Applied Social Studies.
- Bottomoff, J.L. (1994) Using videotaped recordings. In *Critical issues in qualitative research methods* (edited by J.M. Morse) Thousand Oaks, California: Sage Publications. 244-262.
- Brinton Lykes, M. (1997) Activists participatory research among the Maya of Guatemala: constructing meanings of situated knowledge. *Journal of Social Issues* 53, (4) 725-746.
- Broodryk, J. (2002) *Ubuntu: Life lessons from Africa*. Pretoria: Ubuntu School of Philosophy.
- Bryan, M. and Cameron, J. (1998) *The artist's way at work*. London: Pan Books.
- Buchanan, H. and Higson-Smith, C. (2004) Trauma, violence and occupation. In *Transformation through occupation* (edited by R. Watson and L. Swartz), London and Philadelphia: Whurr Publishers. 219-232.
- Buckland, J. (1998) Social capital and sustainability of NGO intermediate development projects in Bangladesh. *Community Development Journal* 33, (3) 236-248.
- Bury, M. (1996) Defining and researching disability: challenges and responses. In *Exploring the divide: illness and disability*. (edited by C. Barnes and G. Mercer). Leeds: Disability Press.
- Campos, M. (1995) Developing livelihoods. In *Innovations in developing countries for people with disabilities* (edited by B. O'Toole and R. McConkey) England: Lisieux Hall Publications. 71-84.
- CDRA (1999/2000) "The High Road: Practice at the Centre" Annual Report. Woodstock, Cape Town.
- CDRA (2000/2001) "Measuring development: Holding Infinity" Annual Report. Woodstock, Cape Town.
- Chambers, R. (1983) *Rural development: putting the last first*. England: Longman Scientific and Technical.
- Chambers, R. (1993) *Challenging the professions: frontiers for rural development*. London: Intermediate Technology Publications Ltd.
- Chambers, R. (1995) Paradigm shifts and the practice of participatory research and development. In *Power and participatory development: Theory and Practice*. (edited by N. Nelson and S. Wright) London: Intermediate Technology Publications. 30-42.
- Chang, J.C., Mafrin, S.L., Morracco, K.E., Dulli, L., Scandlin, D., Loucks-Sori M.B., Turner, T., Staroneck, L., Dorian, P.N., and Bou-Saada, I. (2003) Helping women with disabilities and domestic violence: strategies, limitations, and challenges for domestic violence programs and services. *Journal of Women's Health (Larchmt)* 12, (7) Sep, 699-708.
- Charlton, R. (1998) *Nothing about us without us: Disability oppression and empowerment*. Berkeley, Los Angeles, London: University of California Press.
- Christiansen, C. (1997) Acknowledging a spiritual dimension in occupational therapy practice. *American Journal of Occupational Therapy* 51, (3) 169-172.
- Christians, C.G. (2000) Ethics and politics in qualitative research. In *Handbook of qualitative research. Second edition*. (edited by N.K. Denzin and Y.S. Lincoln), California, London, New Delhi: Sage Publications, Inc. 133-155.

- Cilliers, L. (ed) (2004) *Disability Policy in action: South Africa's Integrated National Disability Strategy explained*. Cape Town: DPSA.
- Clandinin, D.J. and Connelly, F.M. (2000) *Narrative inquiry: Experience and story in qualitative research* San Francisco: Jossey-Bass Publishers.
- Clarkson, P. (1994) *The Achilles Syndrome: Overcoming the secret fear of failure* Dorset: Element Books Ltd.
- Cockburn, A. (2003) *Growing the grassroots: A handbook for people with disabilities who serve as local government councilors*. DPSA: Cape Town.
- Coleridge, P. (1993) *Disability, Liberation and Development* U.K.: Oxfam.
- Coleridge, P. (1999a) 'Development, Cultural and Disability: The Example of Afghanistan'. In *Disability and Development: learning from action and research on disability in the majority world* (edited by E. Stone), The Disability Press, Leeds. 149-167.
- Coleridge, P. (1999b) Disability and Culture. In *CBR in transition: Selected readings in community based rehabilitation. Asia Pacific Disability Rehabilitation Journal* (edited by M. Thomas and M.J. Thomas) **Series I**. January, 21 – 39.
- Coleridge, P. (2004) CBR as part of community development and poverty reduction. Keynote speech. CBR Africa regional conference Lilongwe, Malawi, 31 August – 3 September.
- Cornielje, H. (1993) A local disability movement as part of a Community Based Rehabilitation programme. In *The handicapped community*. (edited by H. Flinkenflügel), Amsterdam: VU University Press.
- Cornielje, H. (1999) Towards a public health perspective on rehabilitation. In *Cross-cultural rehabilitation: An international perspective* (edited by R.L. Leavitt) London: W.B. Saunders. 365-375.
- Crotty, M., Finucane, P. and Ahern, M. (2000) Teaching medical students about disability and rehabilitation: methods and student feedback. *Medical Education* **34**, (8) Aug. 659-64.
- Denzin, N.K. and Lincoln Y.S. (1998a) The art of interpretation, evaluation, and presentation. In *Collecting and interpreting qualitative materials* (edited by N.K. Denzin and Y.S. Lincoln) Thousand Hills, California: Sage publications. 275-282.
- Denzin, N.K. and Lincoln Y.S. (1998b) *Strategies of Qualitative inquiry*. Thousand Hills, California: Sage publications.
- Denzin, N.K. and Lincoln, Y.S. (2000) Introduction: The discipline and practice of qualitative research. In *Handbook of qualitative research. Second edition*. (edited by N.K. Denzin and Y.S. Lincoln) California, London, New Delhi: Sage Publications, Inc. 1-29.
- Department of Education (2002) *Inclusive Education: Draft conceptual and operational guidelines for the implementation of inclusive education – Full service schools (second draft)*. Pretoria: Department of Education Directorate. October.
- Department for International Development (DFID) (2000) – Disability, poverty and development. Issue paper. Accessed on 25 May 2005 from <http://www.dfid.gov.uk/pubs/files/disabilitypovertydevelopment.pdf>
- Department of Health (1997) *White Paper For The Transformation Of Health Systems In South Africa*. Pretoria: Government Printer. April.
- Department of Health. (2000) *National Rehabilitation Policy*. Pretoria: Government Printer
- Department of Labour (1998) *Employment Equity Act*. Pretoria: Government Printer

Department of Labour (1998) Skills Development Act. Pretoria: Government Printer

De Koning, K. & Martin, M. (Eds)(1996) *Participatory Research in Health: Issues and Experience*. Johannesburg: NPPHCN; London and New Jersey: Zed Books Ltd.

De Swardt, C. (2002) Poverty in Urban Cape Town. In Haricharan S and Rendall-Mkosi K, "The Joint Primary Health Care Programme, Final Evaluation Report". December. Annexure 8. Zanempilo Health Project, Cape Town.

De Wet, J. (2000) The study of change and continuity in the worldview of isiXhosa-speaking school leavers in their quest to succeed in the world of work without abandoning their African identity. Unpublished PhD thesis. University of Cape Town.

Dolan, C., Concha, M.E. and Nyathi, E. (1995) Community rehabilitation workers: do they offer hope to disabled people in South Africa's rural areas? *International Journal of Rehabilitation Research* 18, (3) 187-200.

do Rozario, L. (1997) Spirituality in the lives of people with disability and chronic illness: a creative paradigm of wholeness and reconstitution. *Disability and Rehabilitation* 19 (10) October, 427-34.

Doyal, L. (1983) Poverty and disability in the Third World: the crippling effects of underdevelopment. In *A cry for health: poverty and disability in the Third World*. (Edited by O. Shirley) London: The Third World Group for Disabled People and AHRTAG. 7-14.

Doyal, L. (1995) *What makes women sick. Gender and the political economy of health*. London: Macmillan.

Doyal, L. (2003) Sex and gender: The challenges for epidemiologists. *International Journal of Health Services*. 33, (3) 569-579.

Driedger, D., Feika, I. And Batres, E.G. (1996) *Across Borders: women with disabilities working together*. Canada: Gynergy Press.

Duncan, M. (2004) Promoting mental health through occupation. In *Transformation through occupation* (edited by R. Watson and L. Swartz) London and Philadelphia: Whurr Publishers. 198-218.

Duncan, M., Buchanan H. and Lorenzo, T. (2005) Politics in occupational therapy education: a South African perspective. In *Occupational Therapy without borders: learning from the spirit of survivors*. (edited by F. Kronenberg, Simo Algado, S., and Pollard, N.) Edinburgh. London: Elsevier Ltd.

Dyantyi, R. and Frater, W. (2004) Local economic development in Khayelitsha. SALRU, UCT: Department of Constitutional Development.

Dyer, W. (2001) *There is a spiritual solution to every problem*. London: Thorsons.

Eiesland, N.L. (1995) *The disabled god: Towards a liberatory theology of disability*. Nashville: Abingdon Press.

Evans, P.J., Zinkin, P., Harpham, G., and G. Chanudury, G. (2001) Evaluation of medical rehabilitation in community based rehabilitation. *Social Science and Medicine* 53, 333-348.

Farmer, A. (2000) Fully entitled. The reproductive rights of women with disabilities. *Reproductive Freedom News* 9, (2) Feb, 1,3.

Fine, M., Weis, L., Weseen, S. and Wong, L. (2000) For whom? Qualitative research, representations, and social responsibilities. In *Handbook of qualitative research. Second edition*. (edited by N.K. Denzin and Y.S. Lincoln) California, London, New Delhi: Sage Publications, Inc. 107-133.

Kincheloe, J.L. and McClaren, P. (2000) Rethinking critical theory and qualitative research. In *Handbook of qualitative research. Second edition.* (edited by N.K. Denzin and Y.S. Lincoln), California, London, New Delhi: Sage Publications, Inc. 279-314.

French, S. (2001) *Disabled people and employment: a study of the working lives of visually impaired physiotherapists.* Aldershot: Ashgate.

Finkelstein, V. (1991) Working with able-bodied people. May. Accessed through the Disability Archive, Centre for Disability Studies, University of Leeds. Accessed from <http://www.leeds.ac.uk/disability-studies/archiveuk/finkelstein/finkelstein6.pdf>

Finkelstein, V. (1993) Disability: a social challenge or an administrative responsibility. In *Disabling barriers – enabling environment* (Edited by J. Swain, V. Finkelstein, S. French and Oliver, M.) London: Sage Publications. 34-43.

Finkelflugel, H. (2004) *Empowered to differ.* Rotterdam, Netherlands.

Finlayson, M. and Edwards, J. (1995) Integrating concepts of health promotion and community into occupational therapy practice. *Canadian Journal of Occupational Therapy.* **62**, 70-75.

Flower, J. and Wirz, S. (2000) Rhetoric or reality? The participation of disabled people in NGO planning. *Health policy and planning* **15**, (2) p177-85

Foster, M. (1993) Management and organizational development lectures, MSc in Disability Studies Centre for International Child Health, University College London.

Foster, M. (1996) SACLA workshops, Cape Town, April.

Fourie, M., Galvaan, R. and Beeton, H. (2004) The impact of poverty: the potential lost. In *Transformation through occupation* (edited by R. Watson and L. Swartz) London and Philadelphia: Whurr Publishers. 69-84.

Fox, M. (1995) *The reinvention of work: a new vision of livelihood for our time.* San Francisco: Harper.

French, S. (1993) Disability, impairment or something in between? In *Disabling barriers –enabling environment* (Edited by J. Swain, V. Finkelstein, S. French and Oliver, M.) London: Sage Publications.

French, S. (2001) *Disabled people and employment: a study of the working lives of visually impaired physiotherapists.* Aldershot: Ashgate.

Giddens, A. (2001) *Sociology.* Cambridge: Polity.

Goosen, M. and Klugman, B. (eds) (1996) *The South African Women's Health Book* Cape Town: Oxford University Press

Giacaman, R. (2001) A community of citizens: disability rehabilitation in the Palestinian transition to statehood. *Disability and Rehabilitation* **23**, (14) Sep 20, 639-44.

Gueye, S. P. (1999) African renaissance as an historical challenge. In *African Renaissance* (Edited by Makgoba, M. W.) pp243-264. Sandton: Mafube Publishing and Cape Town: Tafelberg Publishers.

Hagey, R. (1997) The use and abuse of participatory action research. *Chronic diseases in Africa.* **18** (1) 1-4. Accessed on [http://www.phac-aspc.gc.ca/publicat/cdic-mcc/18-1/a\\_e.html](http://www.phac-aspc.gc.ca/publicat/cdic-mcc/18-1/a_e.html)

Haricharan, S. (2003) Distilling the Partnership Lessons. Mid term review of MPhil in Disability Programme Link programme, University of Cape Town.

Haricharan, S., and Rendall-Mkosi, K. (2002) "The Joint Primary Health Care Programme, Final Evaluation Report". December. Annexure 8. Zanempilo Health Project, Cape Town.

- Hartley, S. (ed) (2002) *CBR: A participatory strategy in Africa*. London: University College London, Centre for International Child Health.
- Hartley, S., Nganwa, A. and Kisanji, J (2002) Professionals' participation in CBR programmes. In *CBR: A participatory strategy in Africa* (edited by S.Hartley (2002), London: University College London, Centre for International Child Health. 72-85.
- Hartley, S., and Wirz, S. (2002) Development of a 'communication disability model' and its implications on service delivery in low-income countries. *Social Science and Medicine* **54**, 1543-1557.
- Hermanus, K. (ed) (2000) *Building an inclusive community: a disability perspective*. Cape Town: SACLA Rehabilitation Project.
- Hess, L. A. (2003) Consumers' Needs and Perceptions of a Community Based Rehabilitation Project. Unpublished Master's thesis in Public Health. School of Public Health, University of Western Cape.
- Hill, M. (1991) Race and disability. In the Open University (ed) *Disability- identity, sexuality and relationships: Readings*, K665Y course. Milton Keynes: The Open University Press.
- Holloway, I. (1997) *Basic concepts for qualitative research*. Australia: Blackwell Science.
- Hope, A. and Timmel, S. (1995) *Training for Transformation: A Handbook for Community Workers Revised Edition*. Zimbabwe: Mambo Press.
- Hudson, T. (1995) Signposts to spirituality: Towards a closer walk with God. Cape Town: Struik Christian Books.
- Hunt, P. (1981) Settling accounts with the parasite people: A critique of "A life apart" by E.J. Miller and G.V. Gwynn. *Disability Challenge* **1** May, 37-50.
- ILO/UNESCO/WHO (1994) *Community Based Rehabilitation*. Joint Position Paper. Geneva: WHO.
- Ingstad, B. (1995) "Mpho ya Modimo" – A gift of God: Perspectives on attitudes towards disabled persons. In *Disability and culture* (edited by B. Ingstad, and S. Whyte) Los Angeles: University of California Press. 246-263.
- Ingstad, B. (1997) *Community-based rehabilitation in Botswana: The myth of the hidden disabled*. New York, London, Canada: The Edwin Mellen Press.
- Ingstad, B. (1999) The myth of disability in developing nations. *LANCET* **354** (9180): 757-758. August, 28.
- Kabeer, N. (2000) Reflections on the measurement of women's empowerment. In *Discussing women's empowerment: theory and practice*. (edited by Sida studies no. 3) Stockholm: Sida. 17-57.
- Kandyomunda, B., Dube, S., Kangere, M. and Gebretensay, M. (2002) The role of local NGOs in promoting participation in CBR. In *CBR: A participatory strategy in Africa* (edited by S.Hartley (2002), London: University College London, Centre for International Child Health. 137-155.
- Kaplan, A. (1996) *The development practitioner's handbook*. London, Chicago: Pluto Press.
- Khoza, R.J. (1999) The institutional structures that should underpin the African Renaissance. In *African Renaissance* (Edited by Makgoba, M. W.) Sandton: Mafube Publishing and Cape Town: Tafelberg Publishers. 279-288.
- Kitchin, R. (2001) Using participatory action research approaches in geographical studies of disability: some reflections. *Disability Studies Quarterly*. **21**, (4) 61-69. Fall.



Kiyosaki R.T. with Lechter, S. L. (1997) *Rich Dad, Poor Dad*. New York: Warner Books.

Koka, K. D. (2002) 'Foreword' In *Ubuntu: Life lessons from Africa* (edited by J. Broodryk) Pretoria: Ubuntu School of Philosophy. i-v.

Kreftig, L. (1991) "Rigor in Qualitative Research: The Assessment of trustworthiness" *American Journal of Occupational Therapy* (45), 214 – 222.

Kreftig, L. (1992) "Evaluation in CBR". Report from seminar on Community -Based Rehabilitation (CBR), Limuru, Kenya, August 31 - September 3.

Kretschmar, L. (1995) Women and culture: ecclesial and cultural transformation. In *Many cultures, one nation: Festschrift for Beyers Naude* (edited by C. Villa-Vicencio and C. Niehaus) Cape Town: Human and Rousseau. 90-104.

Lang, R. (2000) The role of NGOs in the process of empowerment and social transformation of people with disabilities. In *CBR in transition: Selected readings in community based rehabilitation. Asia Pacific Disability Rehabilitation Journal* (edited by M. Thomas and M.J. Thomas) **Series 1**, January, 1 – 20.

Lawana, N., Mxi, N., Ntsoko, L. and Lorenzo, T. (2003) Community rehabilitation workers: creating links between children and adults with intellectual disabilities, their families and the communities of Khayelitsha and Nyanga. Poster presentation at Down Syndrome South Africa Conference, East London, October.

Leavitt, R.L. (ed) (1999) *Cross-cultural rehabilitation: An international perspective*. London: W.B. Saunders.

Lincoln, Y.S. (1992) Sympathetic connections between qualitative methods and health research. *Qualitative Health Research* 2 (4), November, 375-391.

Lipson, J.G. (1994) Ethical issues in ethnography. In *Critical issues in qualitative research methods* (edited by J.M. Morse) Thousand Oaks, California: Sage Publications. 333 –355.

Lorenzo, T. (1991) To a different drum. Paper presented at the National Conference of South African Association of Occupational Therapists. Bloemfontein.

Lorenzo, T. (1994) The identification of continuing education needs for community rehabilitation workers in a rural health district in South Africa. *International Journal of Rehabilitation Research*. 17, (3) 241-250.

Lorenzo, T. and Katzman, R. (1997) Reports on training workshops for parents of disabled children, Lesotho Society for Mentally Handicapped Children. Maseru, Lesotho.

Lorenzo, T. (1998a) "Who's training who?: Building equitable partnerships". Paper presented at the Early intervention in Child Mental Health conference, Johannesburg, January.

Lorenzo, T. (1998b) Creative approaches in training to shift power. Paper presented at Early Intervention in Child Mental Health conference, Johannesburg, January.

Lorenzo, T. (1999) 'My life has totally changed': towards social transformation for disabled women in Khayelitsha". Paper presented at National Conference for OTASA, July.

Lorenzo, T. and January, M. (1999) Drawing water from the well: the wishes of disabled women for social transformation in the Western Cape" Poster presented at the OTASA conference, July, Johannesburg. Poster presented at 2<sup>nd</sup> International Women's Health Conference, Edinburgh, Scotland, and Poster presentation at the national conference for OTASA, July, Johannesburg.

Lorenzo, T. and Saunders, C. (1999) A general evaluation of the SACLA Rehabilitation Project, Cape Town, October (unpublished).



Lorenzo, T. and Sait, W. (2000) Creating partners in disability: lighting the candle in social human rights development. Report for the SCF Global Review on community-based rehabilitation – Swaziland. March. Commissioned by SCF Swaziland. February.

Lorenzo, T., Mdlolokolo, P., January, M. and Mguda, N. (2001) The Value of Ubuntu in Social and Economic Transformation: a renewed hope through storytelling for disabled women in South Africa. Poster presentation at South African Association of Women Graduates conference at University of Cape Town, February.

Lorenzo, T., Mdlolokolo, P., January, M. and Mguda, N. (2001) Building capacity of disabled women for partnerships in research and development. A seminar on for the UWC School of Public Health Summer School, February. Seminars presented in Mpumalanga and Northern Province for the District Rehabilitation Teams and Disabled Women's Development Programme of DPSA, March.

Lorenzo, T. (2001) Collective action for social change – disabled women in the Western Cape. *AGENDA* 47, 89-94.

Lorenzo, T. (2001) The Journey is Long: Disabled Women rebuild *Ubuntu* in Rehabilitation through storytelling. Paper presented at the 2<sup>nd</sup> OTARG conference, Uganda, 23-27 July.

Lorenzo, T. (2001) Storytelling by disabled women reveal the training and research needs of health professionals. Paper presented at the 2<sup>nd</sup> OTARG conference, Uganda, 23-27 July.

Lorenzo, T. (2002) Developing Competence for Partnerships: The Voice of Occupational Therapy Students in Cape Town South Africa. Poster presentation at World Federation of Occupational Therapy Conference, June, Stockholm, Sweden.

Lorenzo, T., Saunders, C., January, M. and Mdlolokolo, P. (eds) (2002) *On the road of hope: Stories told by disabled women in Khayelitsha*. Cape Town: Division of Occupational Therapy, University of Cape Town.

Lorenzo, T. (2003) No African Renaissance Without Disabled Women: A New Way Of Looking At Social And Economic Development Of Disabled Women In South Africa. *Disability and Society*, 18, (6) 759-778. October.

Lorenzo, T. (2004) Equalising opportunities for occupational engagement: disabled women's stories. In *Transformation through occupation* (edited by R. Watson and L. Swartz) London and Philadelphia: Whurr Publishers. 85-102.

Lorenzo, T. and Cloete, L. (2004) Promoting occupations in rural communities. In *Transformation through occupation* (edited by R. Watson and L. Swartz) London and Philadelphia: Whurr Publishers. 268-286.

Lorenzo, T., Toni, M. and Priestley, M. (in press) Disability Studies: engaging activism and academia for social change. In *Disability and social change: A South African agenda* (edited by B. Watermeyer, L. Swartz, T. Lorenzo, M. Schneider, and M. Priestley) Cape Town: HSRC.

Lorenzo, T. van Niekerk, L., and Mdlolokolo, P. (in press) Negotiating partnerships *Disability and Rehabilitation* (accepted 2004)

Loveday, M. (1991) CBR workers: a South African training manual. Cape Town: SACLA Health Project.

Loveday, M. (1993) An evaluation of the SACLA Rehabilitation Worker Project in Cape Town, South Africa 1992-1993. Submitted for MPhil (Maternal and Child Health) Department of Paediatrics and Child Health. University of Cape Town.

Makgoba, M. W. (ed) (1999) *African Renaissance*. Sandton: Mafube Publishing and Cape Town: Tafelberg Publishers.

- Marks, D. (1999) Dimensions of oppression: theorising the embodied subject. *Disability and Society* **14**, (5) 611-626.
- Marshall, C. and Rossman G.B. (1995) *Designing Qualitative Research*. London: Sage Publications.
- Matthews, M.B. and Huberman, A.M. (1994) *Qualitative data analysis*. London: Sage Publications.
- Mattingly, C. (1991) Narrative Reflections on Practical Actions: Two learning experiments in reflective storytelling. In *The Reflective Turn: Case studies in and on educational practice* (edited by D.A. Schon), New York: Teachers College Press. 235-257.
- Max-Neef, M.A. (1991) *Human Scale Development*. London: The Apex Press.
- Max-Neef, M.A. (1995) Human Scale Development. In *Training for Transformation: A Handbook for Community Workers Revised Edition*. Hope, A. and Timmel, S. (1995) Zimbabwe: Mambo Press.
- Mazwai, T. (1999) Epilogue: Bricks and mortar for the African Renaissance. In *African Renaissance* (Edited by Makgoba, M. W.) Sandton: Mafube Publishing and Cape Town: Tafelberg Publishers. 417-428.
- Mbeki, T. (1999) Prologue. In *African Renaissance* (Edited by Makgoba, M. W.) Sandton: Mafube Publishing and Cape Town: Tafelberg Publishers. xiii-xxi.
- Mbigi, L. (1997) *UBUNTU: The African dream in management*. Johannesburg: Knowledge Resources (Pty) Ltd.
- Mbigi, L. and Maree, J. (1995) *UBUNTU: The spirit of African transformation management*. Johannesburg: Knowledge Resources (Pty) Ltd.
- McColl, M.A. Bickenbach, J., Johnston, J., Nishihana, S., Schumaker, M., Smith, K., Smith, M. and Yealland, B. (2000) 'Spiritual issues associated with traumatic-onset disability' *Disability and Rehabilitation* **22**, (12) 555-564 August.
- McColl, M.A. and Boyce, W. (2003) Disability advocacy organizations: a descriptive framework. *Disability and Rehabilitation* **25**, (2) April 22, 380-392.
- McMillan, J.H. and Schmacher, S. (2001) *Research in education: a conceptual introduction*. Fifth edition. New York. London: Longman Inc.
- Mda, L., Schneider, M. and Lagerdien, F. (1996) Disability. In *The South African Women's Health Book* (edited by M. Goosen and B. Klugman) Cape Town: Oxford University Press. 173-193.
- Meer, S. (ed) (1998) *Women speak: reflections on our struggles 1982-1997*. Cape Town: Kwela Book.
- Meulenberg-Buskens, E. (1996) Critical awareness in participatory research: an approach towards teaching and learning. In *Participatory Research in Health: Issues and Experience*. (Edited by K. De Koning & M. Martin) Johannesburg: NPPHCN; London and New Jersey: Zed Books Ltd. 40- 49.
- Meulenberg-Buskens, E. (1999) *Leadership and Facilitation in Participatory Research and Action*. MRC, Cape Town: Research for the Future. August
- Miles, M. (1995) 'Disability in an Eastern Religious Context: historical perspectives' *Disability and Society* **10** (1) 49-69.
- Miles, S. (1996) Engaging with the Disability Rights Movement: the experience of community-based rehabilitation in southern Africa. *Disability and Society*. **11**(4) 501-517.
- Miller, J. and Glassner, B. (1997) "The "Inside" and the "Outside": Finding realities in interviews In *Qualitative research: Theory, method and practice* (edited by D. Silverman) London: Sage. 99-112.

- Mirembe, J. and Hartley, S. (2002) CBR in Africa: The way forward. In *CBR: A participatory strategy in Africa* (edited by S. Hartley) London: University College London, Centre for International Child Health. 197-207.
- Morgan, G. (1993) *Imaginization: the art of creative management*. Newbury Park, London, New Delhi: Sage Publications.
- Morgan, D. (1996) *Family connections*. Cambridge: Polity Press.
- Morris, J. (1991) *Pride against prejudice*. London: Women's Press.
- Morris, J. (1993) *Independent lives: community care and disabled people*. Basingstoke: Macmillan.
- Morris, J. (1998) Feminism, gender and disability. Seminar paper presentation. Australia. February. Accessed from <http://www.leeds.ac.uk/disability-studies/archiveuk/archframe.htm>
- Morse, J.M. (1998) Designing funded qualitative research. In *Strategies of qualitative inquiry*. (edited by N.K. Denzin and Y.S. Lincoln) Thousand Oaks, London, New Delhi: Sage Publications. 56-85.
- Mosala, I. (1995) Spirituality and struggle: Black and African theologies. In *Many cultures, one nation: Festschrift for Beyers Naude* (edited by C. Villa-Vicencio and C. Niehaus) Cape Town: Human and Rousseau. 79-89.
- Mpagi, J.S. (2002) Government's role in CBR. In *CBR: A participatory strategy in Africa* (edited by S.Hartley) London: University College London, Centre for International Child Health. 86-96.
- Ndaziboneye, B. (2002) People with disabilities 'owning' CBR. In *CBR: A participatory strategy in Africa* (edited by S.Hartley) London: University College London, Centre for International Child Health. 106-116.
- Nelson, N. and Wright, S. (eds) (1995) *Power and participatory development: Theory and Practice* London: Intermediate Technology Publications.
- Netshitenzhe, J. (1999) The media in the African Renaissance. In *African Renaissance* (Edited by Makgoba, M. W.) Sandton: Mafube Publishing and Cape Town: Tafelberg Publishers. 376-385.
- Neufeldt, A. (1995) Self-directed employment and economic independence in low-income countries. In *Innovations in developing countries for people with disabilities* (edited by B. O'Toole and R. McConkey) England: Lisieux Hall Publications. 161-182.
- Nolan, M. and Nolan, J. (1999) Rehabilitation, chronic illness and disability: the missing elements in nursing education. *Journal of Advanced Nursing* 29, (4) Apr 958-66.
- Nosek, M.A., Hughes, R.B., Swedlund, H.B. and Swank P. (2003) Self-esteem and women with disabilities. *Social Science and Medicine* 56, 1737 – 1747.
- Nosek, M.A., Hughes, R.B., Howland, C.A., Young, M.E., Mullen, P.D., and Shelton, M.L. (2004) The meaning of health for women with physical disabilities: qualitative analysis. *Family Community Health* 27, (1) Jan-Mar, 6-21.
- Nouwen, H. (1976) *Reaching out*. William Collins Sons and Co. Ltd.
- Odetta, F., Yoshida, K.K., Israel, P., Li A., Ullman, D., Colantonio, A., Macle, H., and Locker, D. (2003) Barriers to wellness activities for Canadian women with physical disabilities. *Health Care for Women International* 24, (2) Feb, 125-34.
- Office of Deputy President (1997) *The White Paper on an Integrated National Disability Strategy*. Western Cape: Rustica Press.

- Olesen, V.L. (2000) Feminisms and qualitative research at and into the new millennium. In *Handbook of qualitative research. Second edition.* (edited by N.K. Denzin and Y.S. Lincoln) California, London, New Delhi: Sage Publications, Inc. 215-256.
- Oliver, M. (1990) *The politics of disablement: critical texts in social work and the welfare state.* London: Macmillan Press Ltd.
- Oliver, M. (1992) Changing the social relations of research production. *Disability, handicap and Society* 7, (2) 101-114.
- Oliver, M. (1996) *Understanding disability: from theory to practice.* London: Macmillan Press Ltd.
- Oliver, M. (1997) Emancipatory research: realistic goal or impossible dream? In *Doing Disability Research* (edited by C. Barnes and G. Mercer) Leeds: The Disability Press. 15-31.
- Oliver, M. (1999) Final accounts and the parasite people. In *Disability discourse* (edited by M. Corker and S. French) Buckingham Press: Open University Press.
- Oliver M (2004) "The social model in action: If I had a hammer" In *Implementing the social model of disability: Theory and research* (Edited by C. Barnes and G. Mercer) Leeds: The Disability Press. 18-31.
- O'Toole B. and McConkey, R. (eds) (1995) *Innovations in developing countries for people with disabilities.* England: Lisieux Hall Publications.
- Peck, M. S. (1987) *The different drum: community-making and peace.* London: Arrow Books.
- Peterson, P.A. and Quarstein, V.A. (2001) Disability awareness training for disability professionals. *Disability and Rehabilitation* 23, (1) Jan 15, 43-8.
- Philpott, S. (1992) A community empowerment approach to work with the disabled. *South African Journal of Occupational Therapy* 22, (1) 26-30. May
- Polit, D.F. and Hungler, B.P. (1997) *Essentials of Nursing Research: Methods, Appraisal and Utilization Fourth Edition.* Philadelphia: Lippincott.
- Price, P. and Kuipers, P. (2000) CBR action research: current status and future trends. In CBR in transition: Selected readings in community based rehabilitation. *Asia Pacific Disability Rehabilitation Journal* (edited by M. Thomas and M.J. Thomas) Series 1. January, 55 – 68.
- Priestley, M. (1997) Who's research: a personal audit. In *Doing Disability Research* (edited by C. Barnes and G. Mercer) Leeds: The Disability Press. 88-107.
- Priestley, M. (1999) *Disability politics and community care.* Philadelphia: J.Kingsley London: Regional Studies Association.
- Rafi, M. and Chowdhury, A.M.R. (2000) Human rights and religious backlash: the experiences of a Bangladeshi NGO. *Development in Practice* 10, (1) 19 –30.
- Ramadan (1997) Facing the backlash: one's women's experience in Yemen. In *Gender and disability: Women's experiences in the Middle East.* (by L. Abu-Habib). UK and Ireland: Oxfam. 60-66.
- Ramphel, M. (2002) *Steering the stars: Being young in South Africa* Cape Town: Tafelberg.
- Read, J. (2000) *Disability, the family and society: listening to mothers.* Buckingham, Philadelphia: Open University Press.
- Reason, P. (ed) (1994) *Participation in Human Inquiry.* London: Sage Publications.



- Reason, P. (1998) Three approaches to participative inquiry. In *Strategies of qualitative inquiry*. (edited by N.K. Denzin and Y.S. Lincoln) Thousand Oaks, London, New Delhi: Sage Publications. 261-291.
- Reeve, D (2004) Psycho-emotional dimensions of disability and the social model. In *Implementing the social model of disability: Theory and research* (edited by C. Barnes and G. Mercer) Leeds: The Disability Press. 83-100.
- Rifkin, S.B. and Kangere, M. (2002) What is participation? In *CBR: A participatory strategy in Africa* (edited by S.Hartley (2002) London: University College London, Centre for International Child Health. 37-49.
- Roger, J. (1998) *Spiritual Warrior: the art of spiritual living*. Los Angeles, California: Mandeville Press.
- Rooth, E. (1995) *Lifeskills: a resource book for facilitators*. Braamfontein: Nolwazi Educational Publishers.
- Rubin, H.J. and Rubin, I.S. (1995) *Qualitative interviewing: the art of hearing data*. London: Sage Publications.
- Rule, S., Lorenzo, T. and Wolmarans, M. (in press) Community based rehabilitation: new challenges. In *Disability and social change: A South African agenda* (edited by B. Watermeyer, L. Swartz, T. Lorenzo, M.Schneider, and M. Priestley) Cape Town: HSRC. (Chapter 22)
- Saunders, C. (1998) Evaluation of Masiphatisane Disability Forum. Report for SACLA Rehabilitation Project. Khayelitsha, Cape Town.
- Scarborough, D. (1999) "The truth about the Truth Commission." The SAIRR exposes the distortions of the Truth Commission. Gospel Defence League. Accessed from [http://www.christianaction.org.za/GDL/Newsletters/1999-july\\_aug.htm](http://www.christianaction.org.za/GDL/Newsletters/1999-july_aug.htm)
- Schneider, M., Claassens M., Kimmie, Z., Morgan, R., Naicker, S., Roberts, A. and McLaren, P. (1999) We also count! The extent of moderate and severe reported disability and the nature of the disability experience in South Africa. Commissioned by the Department of Health, Directorate: Chronic diseases, disabilities and geriatrics. Johannesburg: Community Agency for Social Enquiry. October.
- Schon, D.A. (1991) *The Reflective Turn: Case Studies in and on educational practice* New York: Teachers College Press.
- Selway, D. and Ashman, A.F. (1998) Disability, Religion and Health: A literature review in search of the spiritual dimensions of disability. *Disability and Society* 13, (3) 429-439.
- Shakespeare, T. (2000) *Imagining welfare: Help*. Birmingham: Venture Press.
- Shutte, A. (1993) *Philosophy for Africa*. South Africa: University of Cape Town Press.
- Slim, H. and Thompson, P. (1993) *Listening for a Change: oral testimony and development* London: Panos Publications Ltd.
- Smaling, A. (1998) Dialogical partnerships. The relationship between the researcher and the researched in action research. In *The complexity of relationships in action research*. (Edited by B.Boog, H. Coenen, L.Kenne and R Lammerts) Tilburg: Tilburg University Press. 1-15.
- Smith, E., Murray, S.F., Yousafzai, A.K., and Kasonka, L. (2004) Barriers to accessing safe motherhood and reproductive health services: the situation of women with disabilities in Lusaka, Zambia. *Disability and Rehabilitation* 26, (2) Jan 21, 121-7.
- Stienstra, D., Frieke, Y., D'Aubin, A. and research team (2002) Baseline assessment: Inclusion and disability in World Bank activities. Manitoba, Canada: Canadian Centre on Disability Studies

Stone, E. (1997) From the research notes of a foreign devil: disability research in China In *Doing Disability Research* (edited by C. Barnes and G. Mercer) Leeds: The Disability Press.

Stone, E. (1999) Disability and development in the majority world. In *Disability and development: learning from action and research on disability in the majority world* (edited by E. Stone) Leeds: The Disability Press. 1-18.

Stone, E. (2001) A complicated struggle: disability, survival and social change in the majority world. In *Disability and the life course: Global perspectives* (edited by M. Priestley), pp 50-66. U.K.: Cambridge University Press.

Stone, E. and Priestley, M. (1996) Parasites, pawns and partners: disability research and the role of the non-disabled researchers. *British Journal of Sociology* 47, (4) 699-716.

Stubbs, S. (1999) Engaging with difference: Soul-searching for a methodology in disability and development research. In *Disability and development: learning from action and research on disability in the majority world* (edited by E. Stone) Leeds: The Disability Press. 257-279.

Swain, J. (1993) Taught hopelessness? Or a say for disabled children in schools. In *Disabling barriers – enabling environment* (Edited by J. Swain, V. Finkelstein, S. French and Oliver, M.) London: Sage Publications. 155-162.

Swartz, L. (2004) Rethinking professional ethics. In *Transformation through occupation* (edited by R. Watson and L. Swartz), pp. 289-300. London and Philadelphia: Whurr Publishers.

Taylor, V. (2000) *South Africa: Transformation for human development 2000*. Pretoria: United Nations Development Programme.

Taylor, J., Marais, D. and Heyns, S. (1998) *Community participation and financial sustainability. Action Learning Series – case studies and lessons from development practice*. Cape Town: Juta.

Taylor, V. and Conradie, I. (1997) “We have been taught by life itself”: Empowering women as leaders: the role of development education: University of Western Cape: SADEP.

TCOE (2001/2) Human Scale Development: A brief description. Module 2 AIDS Programme. Mowbray, Cape Town. 4-5.

Telela, R. (1994) Love shouldn't hurt. *SPEAK* 66. In Meer, S. (ed) (1998) *Women speak: reflections on our struggles 1982-1997*. Cape Town: Kwela Book. 91-93.

Thomas, C. (1998) *Female forms: experiencing and understanding disability* Buckingham and Philadelphia: Open University Press.

Thomas, C. (2002) Disability Theory: Key ideas, issues and thinkers. In *Disability Studies Today* (edited by C. Barnes, M. Oliver, and L. Barton) Cambridge: Polity Press. 38-57.

Thomas, C. (2004) Developing the Social relational in the social model of disability: a theoretical agenda In *Implementing the social model of disability: Theory and research*. (edited by C. Barnes and G. Mercer) Leeds: The Disability Press. 32-47.

Thomas, M. and Thomas, M.J. (2000) A discussion of some critical aspects in planning of community based rehabilitation. In *CBR in transition: Selected readings in community based rehabilitation. Asia Pacific Disability Rehabilitation Journal* (edited by M. Thomas and M.J. Thomas) Series 1. January, 84-95.

Thomas, M. and Thomas, M.J. (2002) Some controversies in community based rehabilitation. In *CBR: A participatory strategy in Africa* (edited by S. Hartley) London: University College London, Centre for International Child Health. 13-25.



- Thorn, S. (1004) Secondary analysis in qualitative research: issues and implications. In *Critical issues in qualitative research methods* (edited by J.M. Morse) Thousand Oaks, California: Sage Publications. 263-280.
- Tiroler, G (1995) Learning about the links. *CBR News* (21), Sept-Dec, London: AHRTAG. 4-5.
- Touraine, A. (1981) *The voice and the eye: an analysis of social movements*. Cambridge: Cambridge University Press.
- Townsend, J. (1995) Who speaks for whom? Outsiders re-present women pioneers of the forests of Mexico. In *Power and participatory development: Theory and Practice*. (edited by N. Nelson and S. Wright) London: Intermediate Technology Publications. 83 – 94.
- Townsend, E. (1996) Enabling empowerment: using simulations versus real occupations. *Canadian Journal of Occupational Therapy* **63**, (2) 114-1267.
- Tutu, D. (2004) *God has a dream: A vision of hope for our time*. South Africa: Random House.
- Tyndale, W. (2000) Faith and economics in 'development': a bridge across the chasm? *Development in Practice* **10** (1) February, 9-18.
- University of Cape Town (1996) Mission Statement of the University of Cape Town. Working group of the UCT transformation forum. Affirmed and adopted at the University Assembly, April, 24.
- UN. (1994) *UN Standard Rules on the Equalisation of Opportunities of People with Disabilities*. Vienna: UN.
- Van Niekerk, L., Lorenzo, T. and Mdlokolo, P. (2005) Understanding partnerships in developing disabled entrepreneurs through Participatory Action Research. *Disability and Rehabilitation* (accepted 2004).
- Van Zyl, J. (1994) What is Human Scale Development? A brief overview. Mowbray, Cape Town: The Network for Human Scale Development (Southern Africa).
- Ver Beek, K.A. (2000) Spirituality: a development taboo. *Development in Practice* **10** (1) 31-43.
- Vernon, A. and Swain, J. (2002) Theorising divisions and hierarchies: Towards a commonality or diversity. In *Disability Studies today* (edited by C. Barnes, M. Oliver and L. Barton) Cambridge, UK: Polity Press. 77-97.
- Villa-Vicencio, C. (1995) Telling one another stories: Towards a theology of reconciliation. In *Many cultures, one nation: Festschrift for Beyers Naude* (edited by C. Villa-Vicencio and C. Niehaus), Cape Town: Human and Rousseau. 105-121.
- Watermeyer, B (2000) Psychoanalysis and disability: an exploration of the utility of psychoanalytic methods and analyses in the interrogation of social responses to impairment. MA in Psychology (unpublished thesis) University of Cape Town.
- Watson, R. and Lagerdien, K. (2004) Women empowered through occupation: from deprivation to realized potential. In *Transformation through occupation* (edited by R. Watson and L. Swartz), London and Philadelphia: Whurr Publishers. 268-286.
- Werner, D. (1992) *Disabled Village Children: A guide for community health workers, rehabilitation workers and families*. Palo Alto CA: Hesperian Foundation.
- Werner, D (1995) Strengthening the role of disabled people in CBR programmes. In *Innovations in developing countries for people with disabilities* (edited by B. O'Toole and R. McConkey). England: Lisieux Hall Publications. 15-28.

Werner, D. and Saunders, S. (1995) *Questioning the solution: the politics of primary health care and child survival*. Palo Alto CA: HealthWrights.

Whyte, S. and Muyinda, H. (2002) Finding people where they live: The view from the tricycle in Busia. In *CBR: A participatory strategy in Africa* (edited by S.Hartley), London: University College London, Centre for International Child Health. 127-136.

Wilcock, A.A. (1998) *An occupational perspective of health*. Thorfare, N.Y.: SLACK Inc.

Willmuth, M.E. and Holcomb L. (1993) *Women with disabilities: found voices*. New York: Haworth Press.

Willms, D. G. (1997) You start your research on your being. In *Nurtured by knowledge: Learning to do Participatory Action-Research*. (edited by S.E. Smith, D.G. Willms and N.A. Johnson) New Jersey: Apex.

Wilson, F. and Ramphela, M. (1989) *Uprooting Poverty – the South African Challenge*. Cape Town: David Philip.

Wirz, S. (2000) Training of CBR personnel. In *CBR in transition: Selected readings in community based rehabilitation*. *Asia Pacific Disability Rehabilitation Journal* (edited by M. Thomas and M.J. Thomas) **Series 1**, January, 96 –108.

WHO (2003) Report of International Consultation To Review Community-Based Rehabilitation (CBR). Helsinki. 25-28 May.

Zarb, G. (1997) Researching disabling barriers. In *Doing disability research* (edited by C. Barnes and G. Mercer) Leeds: The Disability Press. 49-66.

# Appendix 1

## Summary of key aspects of the UN 22 Standard Rules

PRECONDITIONS FOR EQUAL PARTICIPATION	
Rule 1: Awareness raising.	Take action to raise awareness in society about persons with disabilities, their rights, their needs, their potential and their contribution. Information and knowledge about disability should be disseminated through the different forms of media such as television, books, newspapers and radio. Information should also be included in school curricula.
Rule 2: Medical care.	Access to treatment, medication and provision of effective medical care to persons with disabilities, including disability training for medical doctors, research on diseases leading to disability prevention and early treatment.
Rule 3: Rehabilitation.	Provide services, support and advice to reach disabled people and their family to sustain an optimum level of independence and functioning. Involve disabled peoples organisations in programme planning.
Rule 4: Support services.	Supply of assistive devices and technical equipment as well as personal assistants and interpreters to assist disabled people to increase their level of independence in their daily living and to exercise their rights.
TARGET AREAS FOR EQUAL PARTICIPATION	
Rule 5: Accessibility.	Make the physical environment accessible, including public transport. Provide access to information and communication by assisting DPOs in this task.
Rule 6: Education.	Equal primary, secondary and tertiary educational opportunities for children, youth and adults with disabilities, in integrated settings, with a specific focus on children and disabled women. Training of teachers in disability issues should be seen as essential.
Rule 7: Employment.	Provide equal opportunities for productive and gainful employment in the labour market, in ordinary workplaces, in both rural and urban areas, at the same time as recognising that disabled people may be able to work small co-operatives. Consider provision of technical assistance, personal assistants and interpreters.
Rule 8: Income maintenance and social security.	Provision of social security and income maintenance for disabled people who may be paid too little, underemployed or unemployed. Consideration given to the extra costs of disability. Carers should receive security and payment. Proper training and assistance in getting a job to be able to live independently and be paid for work.
Rule 9: Family life and personal integrity.	States should promote full participation in family life, and the right to live with their families in a family home. Ensure laws do not discriminate against disabled people with respect to sexual relationships, marriage and parenthood. Provide information to avoid abuse and exploitation by family members. Relief by trained personnel for families.
Rule 10: Culture.	Integrate into and can participate in cultural activities, such as dance, playing music, writing books, acting or painting, as means to express themselves or share experiences with others.
Rule 11: Recreation and sport.	Opportunities for recreation and sport, including travel and tourism.
Rule 12: Religion.	Provide support to go to church, as well as inform ministers and leadership about disability issues to foster participation in the religious life of their communities. Information and reading material should be in accessible formats.

IMPLEMENTATION MEASURES	
Rule 13: Information and research.	Collection and dissemination of information on the living conditions of disabled people.
Rule 14: Policy-making and planning.	Include disability aspects in all relevant policy-making and national planning.
Rule 15: Legislation.	Create the legal bases for measures to achieve the objectives of full participation and equality for disabled people.
Rule 16: Economic policies.	Carry financial responsibility for national programmes and measures to create equal opportunities for disabled people.
Rule 17: Co-ordination of work.	Establish and strengthen national co-ordinating committees, or similar bodies, to serve as a national focal point on disability matters.
Rule 18: Organizations of persons with disabilities.	Recognize the right of organizations of disabled people to represent themselves at national, regional and local levels. Recognize the advisory role of organizations of disabled people in decision-making on disability matters.
Rule 19: Personnel training.	Ensure adequate training at all levels of personnel involved in the planning and provision of programmes and services concerning disabled people.
Rule 20: National monitoring and evaluation. <sup>27</sup>	Continuous monitoring and evaluation of the implementation of national programmes and services concerning the equalization of opportunities for disabled people.
Rule 21: Technical and economic co-operation.	Cooperate in and take measures for the improvement of the living conditions of disabled people in developing countries.
Rule 22: International co-operation.	Participate actively in international cooperation concerning policies for the equalization of opportunities for disabled people.

<sup>27</sup> As recorded in the policy: National monitoring and evaluation of disability programmes in the implementation of the Rules

## Appendix 2

### Time schedule of phases, research methods and creative activities.

Month	Research methods	Creative activity
Phase One: Setting The Scene		
1998 March-May	Preparation and planning	Drawings
June	Storytelling: Area A	
July	Area C	
September	Area B	
December	Areas D and E	
Phase Two: Planning To Take PAR Further		
1999 May and August	NAR workshops: Planning the research	Listening to audio tapes of their stories
September	What is meant by participatory action research (PAR)	Poster
November	Experiences of using public transport	Action reflection dance Critical incident stories
Phase Three: Implementation of actions		
2000 February	NAR workshops: Understanding PAR Reflecting on changes	Drawings
March	Individual experiences of disability	Use object from environment
April	Family attitudes to disability	Picture 'codes'
May	Family and community attitudes to disability	Songs and slogans
June	Skills development and money management Trip to Robben Island to celebrate Youth Day	Workshop at UCT
July	Skills development Member checking	Poster presentation at Uppsala University, Sweden
August – November	Skills development Celebration for National Women's Day, Selling t-shirts, Rural women's workshop in Boland district Year end review	Storytelling T-shirts Presentation by women
September	Participation in Adult Literacy Week	
December:	Organizing Christmas Party	
Phase 4: Dissemination of findings		
2001 February/March	Seminars	Workshops at UWC, Mpumalanga and Limpopo
April	Documentation	Journal article
May	Member checking for seminar at Uppsala University, Sweden	Powerpoint presentation
August	Member checking for OTARG conference, Uganda	Poster presentation
2002 September	NAR workshop with Leeds university staff, Cape Town	Roleplays
December	Zanempilo retrenches all staff	
2003/ 2004	Writing up research Member checking for CBR conference, Malawi	Chapter in book and journal article Poster presentation
<b>Reporting</b> Regular reports were given to the SACLA rehabilitation management team for their progress reports to funders. DPSA Provincial Development team received regularly reports from MJ as the chairperson of the Provincial Disabled Women's Development programme. Annual reports to NRF and MRC were copied and sent to the partner organization		



## Appendix 3

### Example of workshop programme

University of Cape Town, DPSA and SACLA Rehab Project  
Disabled women's participatory action research workshop

**Theme: AFFECTION: DISABILITY AND YOUR FAMILY**

**Date:** 13<sup>th</sup> April 2000

**Venue:** Lutheran Church, Brown's Farm

TIME	TOPIC
9:30 – 10:30	♦ Tea and arrival, opening by prayer
10:30 – 10:50	♦ Welcoming and introduction
10:50 – 11:00	♦ Icebreaker
11:00 – 11:10	♦ "You and your neighbour" – similarities and differences.
11:10 – 11:40	♦ Feedback
11:40 – 12:30	♦ "Disability and your family: looking at your load"
12:30 – 13:00	♦ Feedback
13:00 – 13:30	♦ (Transport)
13:30 – 14:00	♦ Evaluation
14:00 – 14:30	♦ LUNCH!! LUNCH!! LUNCH!!

Opening exercise:

**ENGLISH:** How are you different or similar to your neighbour?

**XHOSA:** *Wahluke njani okanye ufana ngantoni nomelwane wakho?*

Trigger for main activity: pictures of a woman carry tyres and a woman carry pot.

- What is the nature of your load in your family?
- *Unjani umthwalo wakho kowenu?*
- How does your load in your family stop your social and economic development?
- *Umthwalo wakho ekhaya ukuthintela njani ekubeni ukhule ekuhlaleni nangezemali?*
- How does your load foster your social and economic development?
- *Umthwalo wakho ukuphuhlisa njani ukuba ukhule ekuhlaleni nangezemali?*
- What will change the situation for you?
- *Yintoni engatshintsha le meko?*







she is getting  
the grant

I buy clothes for myself  
with my grant

I make clothes  
& sell them to  
buy food

Nomazwi-Sylvia

Sifuna ukhumbano  
Sawungaphela  
ukuba abantu  
bathuthuzekileyo  
ngokuthi sangemini  
Sibongi yeZandla  
Sithengise ukhuzo  
Sancedisane nalemizila  
Sigijimana kuthuthuzekileyo  
ukhuzo sibongi ukhuzo gcinde  
inali

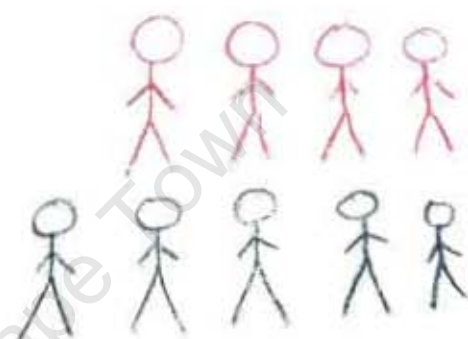
We want to improve  
our situation as disabled  
people by doing  
hard work & sell  
so that we can  
help the grant  
from government  
so that we  
can keep more

Sigakuhlala nabo etshileni nibe isane okokuba  
manincedisane sithengise izigamezali ukhuzo kuthengise  
into ethwayo.  
Iwe'll sit down with them around the  
table & talk with them to help with the  
business & get money so that we can  
be able to buy something to eat



Khwayelitshwa

group



Community

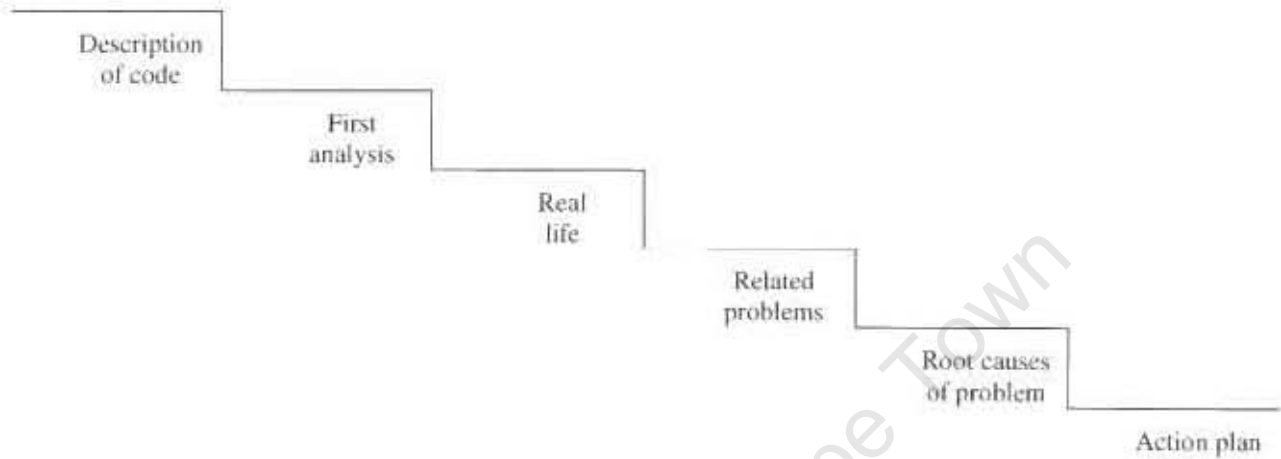


## Appendix 4

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### Six step analysis of data triggers

The discussion moves down step by step in 6 stages.



## Appendix 5

### Specific details on the phases of research

#### Phase 1. Storytelling

Each woman was asked to draw a picture to share their story about their experience of disability. 30 minutes were allowed for drawing. Each woman was then given an opportunity to tell her story to the large group. The workshops concluded with women saying what they would like to see happen next. The workshops were facilitated in Xhosa by the one facilitator, with no translation.

#### Phase 2 Action planning

A workshop was organised in May facilitated by a community organizational development practitioner. She took the women through a reflective process of looking at how they had felt telling their stories, what changes there had been since sharing and what they wanted to do with the stories. One of the difficulties at this workshop was that new women attended who had not participated in the initial storytelling workshop.

As there was insufficient time for action plans during this workshop, it was carried over to a workshop in August. Again, we had the dilemma of inconsistent attendance as many new women joined who had not told their stories and others who had told their stories did not attend. This raised concerns around the sample size and how we would manage the inclusion/exclusion dynamic. The focus of further inquiry was discussed and agreed upon between the women and the research facilitators. A set of questions was identified to explore further. There were five broad domains of action that emerged from the planning.

#### NAR workshop: understanding PAR

The facilitators were conscious of the need to reinforce the notion that the purpose of the research was participatory with an action learning focus. Thus time was spent in two workshops with an interval of five months between them to establish a common understanding of what was meant by PAR (September 1999 and February 2000). During the September workshop the women were divided into small groups. Each group had to produce a drawing to reflect their understanding of PAR, which was presented to the larger group. The purpose of the workshop was to common ground about PAR as a tool for development.

In February 2000, we used a similar format as September to get the women in to small groups to review the research process so far. In the second part of the workshop, to consider the focus for the year ahead, the women were each given a lump of clay. They were asked to form something to reflect any changes that they had experienced and what they hoped for in being part of the research process. They could show what they felt had been achieved and what their goals were for the coming year. Creative activities such as these were used to encourage the women to reflect individually and then collectively. Music from African musicians was played in the background. At the end of the workshop each woman was given the chance to sign a commitment paper if they wanted to participate in the workshops for the next year. Verbal consent was obtained.

#### NAR workshop: transport

In November 1999, the workshop focused on the issue of transport, which had been identified by the women as a critical collective issue that needed action, to use a practical issue to demonstrate the nature of PAR. In small groups of five, women told of their experience of using public transport. A scribe recorded the stories and two groups used a tape recorder to overcome the problem of illiteracy. A spokesperson for each group reported back. We then had a short story from the chairperson for the provincial DPSA (V) who is visually impaired. He spoke on the role of disabled people's organisations (DPOs) to lobby and advocate for better public transport systems. We were really moved by V's story and his challenge to us. We discussed how women should not feel ashamed of their anger about inaccessible transport but rather reflect on what their anger is telling them and how it could be channelled into action to make a difference. At this workshop, it became evident that the women were growing in confidence in sharing how they felt about their experience

of being disabled. In analyzing transcripts of subsequent workshops in phase three, field notes and records of consultative meetings, it was identified as a recurring critical incident.

### **Phase 3: Implementation of actions**

In exploring identity at an individual level in the March workshop, each woman was asked to find an object from the environment that symbolised her identity. Each woman was interviewed briefly by one of the research facilitators about the object she had chosen using a fishbowl approach. The workshop ended with women deciding on actions that they would take before the next workshop.

The April and May workshops focused on the experience of disability at a family level.

In the subsequent workshops from June until November, the women were encouraged to engage in actions between NAR workshops related to issues raised.

In the June workshop, an opening question, 'What does 'creativity' mean to you?' was posed to enable the women to explore how they understood and met the fundamental human needs in an attempt to break the vicious cycle of poverty and disability (Max-Neef, 1991; Van Zyl, 1995; Stone, 2001). To do this, the women were divided into pairs, and then formed small groups to examine how their present skills and strategies could be enhanced to meet their fundamental human needs. After reporting back, skills development clusters were formed where mutual sharing and learning of skills that they identified as potential business initiatives took place between the monthly workshops during the six-month period. These groups included, a handwork cluster that focused on sewing, knitting and crocheting, and the embroidery of food covers; an arts and culture cluster and a catering cluster. The CRWs divided themselves into the different groups according to their skills and interest. There was also a continuous change in membership of groups during the six months.

The women were encouraged to bring any ideas or any requests to each workshop or to convey these through a CRW or one of the facilitators. Business related activities and skills development were organised by SACLA or DPSA. As part of the process, the groups spent one day in a skills-sharing workshop, using a venue outside of Khayelitsha, as the women wanted an outing. Opportunities were sought, e.g. a visit to Robben Island on June 16, Youth Day, which was a public holiday and a Christmas beach braai that were turned into reflective learning activities, as the women were responsible for all the organizing.

### **Phase Four: Dissemination of findings**

The School of Public Health, University of Western Cape requested that we present a two-hour seminar on the experience of women being research partners for their Summer School in February. Following this, two workshop seminars were organised with the Disabled Women's Development Programme in Mpumalanga and Limpopo provinces in the northern part of the country with a large proportion of rural areas. The women presented the findings at these seminars themselves. In response to a request from Uppsala University to attend a CBR workshop, I presented a paper. Poster presentations have been done annually at different conferences so that we maximized the opportunities to let the voices of the women to be heard (see references for details).



## Appendix 6

### Time schedule of phases

Month	Research methods
<b>Phase One: Setting The Scene</b>	
<b>1998</b>	
March-May	Preparation and planning
June	Storytelling: Area A
July	Area C
September	Area B
December	Areas D and E
<b>Phase Two: Planning To Take PAR Further</b>	
<b>1999</b>	NAR workshops:
May and August	Planning the research
September	What is meant by participatory action research (PAR)
November	Experiences of using public transport
<b>Phase Three: Implementation of actions</b>	
<b>2000</b>	NAR workshops:
February	Understanding PAR Reflecting on changes
March	Individual experiences of disability
April	Family attitudes to disability
May	Family and community attitudes to disability
June	Skills development and money management Trip to Robben Island to celebrate Youth Day
July	Skills development Member checking
August – November	Skills development Celebration for National Women's Day, Selling t-shirts, Rural women's workshop in Boland district Year end review
September	Participation in Adult Literacy Week
December:	Organizing Christmas Party
<b>Phase 4: Dissemination of findings</b>	
<b>2001</b>	Seminars
February/March	
April	Documentation
May	Member checking for seminar at Uppsala University, Sweden
August	Member checking for OTARG conference, Uganda
<b>2002</b>	NAR workshop with Leeds university staff, Cape Town
September	
December	Zanempilo retrenches all staff
<b>2003/ 2004</b>	Writing up research Member checking for CBR conference, Malawi

## Appendix 7

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### Informed consent form

#### **Disabled Women's Research Project: SACLA – DPSA - UCT**

*Information sheet to seek informed verbal consent of disabled women who participate in the study. The research facilitators will give the information verbally in Xhosa to the women. The research facilitators will respond directly to any questions before the women give consent.*

We are Theresa Lorenzo, Peliwe Mdlokolo and Marjorie January from the Division of Occupational Therapy, University of Cape Town and Disabled People South Africa, respectively. We are interested in doing a study to explore the opportunities for development of disabled women. We would like to identify the factors that hinder or foster your participation in these opportunities.

The study will involve participation initially in a one-day workshop to tell your story. The nature of the study is such that participants will be involved in deciding the number and the frequency of these workshops. The duration of each workshop will be approximately 5 hours.

We would like your permission to videotape each workshop for the purpose of accurate recording of data. At any time you may request for the video camera to be switched off. In reporting the findings of the study, we will not use your actual names without your permission. Participants will decide together with the research facilitators how to disseminate the findings and the particular target groups.

We would also like your permission to take photographs of the process to use for funding reports, undergraduate and postgraduate teaching, seminars or conference presentations, and any publications that come out of the study. You will be given the opportunity to review the photos before they are used.

Your participation in the study is completely voluntary. You may withdraw from the study at any time. Participants will sign a register at the beginning of each workshop so that we are able to keep a record of attendance.

Many thanks for your co-operation and willingness to collaborate.

### Register of participants

Venue: \_\_\_\_\_

[illegible]

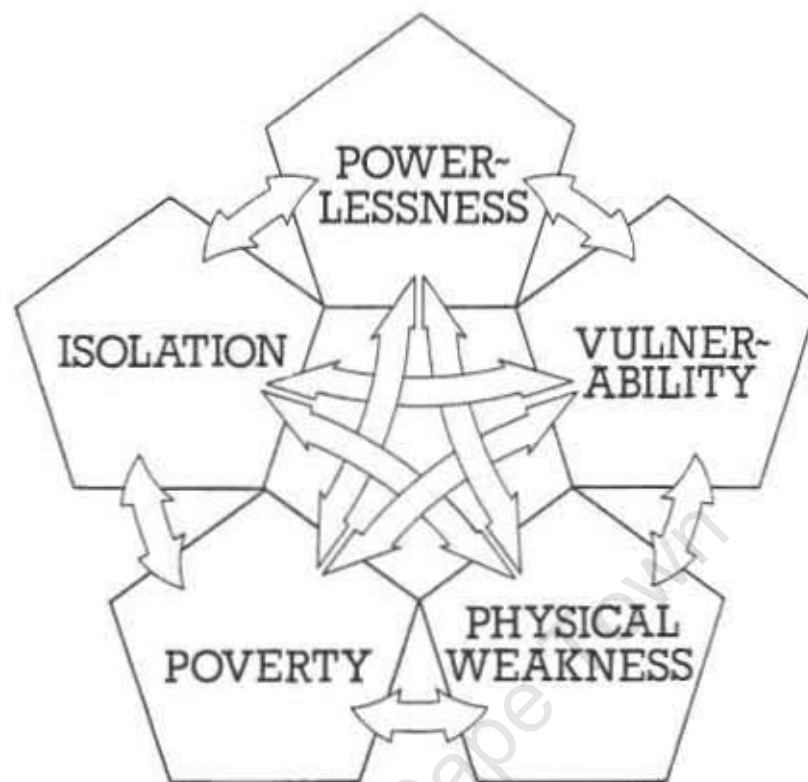
## Appendix 8

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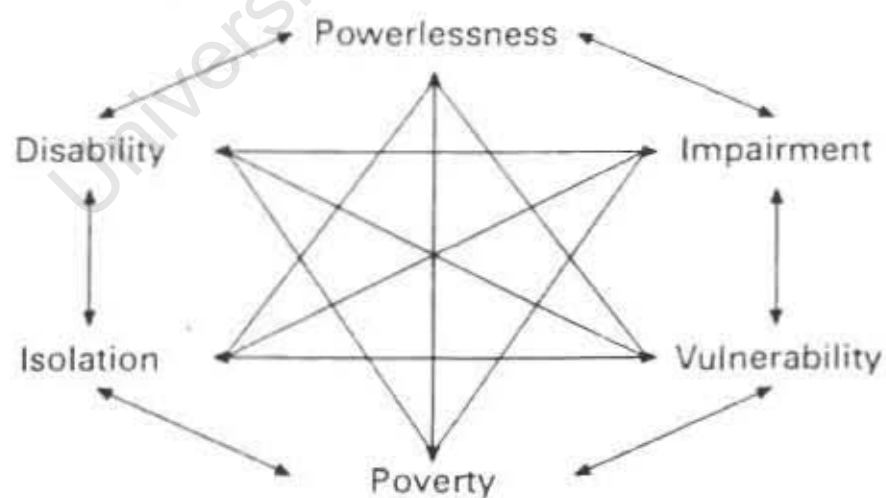
### Deprivation traps

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The deprivation trap (Chambers 1983)



Revised version of the 'deprivation trap' ( Stone 2001)





## Appendix 9

### Monica's story (Chapter 5)

#### Coping as both mothers and fathers

Monica was a regular participant in the PAR study and one of the founder members of the Asoyiki<sup>28</sup> entrepreneurship group. She was a single parent. She stayed with her children in a wooden shack that had corrugated sheets of iron as a roof. Her spirit of resilience was refreshing, as she was confident in her ability to manage family problems with minimal worry and anxiety. Monica became a role model for other women. She tells her story.

*I'm a mother and a father in my house... All my eight children are dependent on me...I'm a disabled mother but I don't rely on that. I don't tell myself that I'm disabled. Why? If I tell my child the right thing and she thinks I'm disabled, she'll do what she thinks is right. I know that's her problem. I concentrate on the child who thinks or sees herself as a child. I leave the one who thinks she's old and when she has a problem, I ask her, "Can you see?" If she doesn't want to listen I show her the door of my house because I was also able to chuck out her father.*

*I have no doubt in my ability to discipline and guide my children despite my impairment. I know when to discipline and let them take responsibility for themselves. I identify myself with the moon. At night the moon provides light although during the day it's the sun that provides light. If my children need education, I don't have problems with that. Like Sivuyile is 16 years and is in high school. His other brothers are outside enjoying themselves. One is in jail, but I don't have problems with that. If I told you and you just decide to go out, it's your own problem.*

*I hear the other women are hurt when their children are in jail. Yes, you get that feeling, if you didn't tell your child that what they are doing is wrong. But if you told him, I won't be hurt. That's why I'm saying I don't have problems if my children want to continue with school and be what they want to be. I don't have any expectations that my children should look after me, because our children get educated for their gain not to help the young ones or make their parents happy.*

*I will continue to be a light for other women who feel heavy with the load of looking after children with no husband or brother to help them. We can be strong together and find ways to provide for our children. We can do everything for ourselves.*

*The most striking aspect of Monica was her love for life and her confidence in parenting. She was a strong role model for other women who found it difficult to manage family conflict. Her story illustrates her strength and ability to manage the social disintegration in her family along with her ability to discipline her children. Her story provides a rich portrayal of the resilience of the women in the face of oppression and their rebellion against practices that caused hardships and suffering. Monica did not see the dependency and multiple responsibilities of families as a burden as other women seemed to. She was, therefore, a potential source of encouragement to other women. She provided inspiration and an example of an alternative way of living with her impairment. Monica found ways to cope with difficulties of raising older children without allowing these issues to make her feel guilty or helpless. She recognized what she could do and also made her children take responsibility for themselves!*

<sup>28</sup> A Xhosa name meaning "We are not afraid".

## Appendix 10

A matrix analysis categorising the existing skills of the women

Handwork	Arts and Culture	Catering	Farming	Crèche	Lifeskills and other
Design African clothes, sew and sell clothes; knitting jerseys and hats, making bags, belts and shoes, bead making, making mats with material pieces.	Do painting, singing, talking, play netball, learn media skills (radio, poetry, writing, drama).	Baking bread and cakes, cooking, selling sweets	Plant and sell mielies, <sup>29</sup> vegetables and fruit, raising chickens.	Child minding, looking after abandoned children, making APT <sup>30</sup> chairs for a crèche of disabled children	Building and developing each other; self care, brick making, building houses, selling, baking and doing house cleaning, washing and ironing other people's clothes; speaking about oneself, preaching and counseling, hairdressing office skills

<sup>29</sup> Corn or maize

<sup>30</sup> Appropriate paper technology: making equipment from cardboard

## Appendix 11

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### Stories of actions

#### Action learning group 4: Drama Training and Community Disability Awareness Workshops

*There must be a workshop and we call families and community members because there are problems that we experience in the community because they don't know what disability is and they give us names. Those things are destroying us inside in our hearts and souls. They call you witch and they say, "The witch is dragging her feet". So in our group we said we should have a workshop that will involve family members and community members because we are like other people (Small group).*

*Yes, we must sit down with our families and tell them about our suffering. There is nothing as important as that (Small group 2).*

From small group discussions, a group expressed strongly that there had to be a change in the stigma and stereotypes that they experienced in the wider community beyond just their family. An important issue for the women was to make their families aware of their suffering and difficulties.

SACLA had funding to carry out a health promotion project on disability awareness and advocacy in the community. The organisation contracted the Cape Arts Project, a community-based drama organization, to train a group of women, men and parents of disabled children in developing messages on disability that could be portrayed through a play. The purpose of the plays was two-fold: health promotion and social integration of disabled children and adults in community events. The disability awareness play was performed at a number of primary schools in the area as well as at community events. This action indicated a significant change in their view of the root cause of their underdevelopment, which they felt was linked to insufficient awareness and information related to disability issues.

The idea of changing attitudes to disability in the family and community by sharing their experiences also extended to ways in which their family members could assist in the sustainability of their small business initiatives. As one group expressed:

*We'll sit down with our families around the table and talk with them to help with the business and get money so that we can be able to buy something to eat.*

Similarly, another group felt:

*When you are selling your stuff, the family that is not working must help you. You as a disabled person have a business and then you have to buy food so that this person can eat.*

This desire was extended further by a suggestion to use the media to reach the community:

*We also said there can be a workshop in the community whereby community members and families could be called so that they can understand disability and understand our problems as community members. CRWs can do workshops in the community, even at Radio Zibonele and announce there but there is only one station. You can't get it in other areas. We want even Radio Xhosa/Umhlobo Wenene where all the areas can hear ... others can listen to Radio Zibonele and if they can't get the station go to the neighbour and listen so that they can have clearer understanding.*

Using a PAR process meant that the research facilitators were able to encourage the women to be accountable and learn from each other. There was an incident where the drama group had organized and advertised a concert as a fundraiser. Many of the women went along to give their support only to find out that the event had been cancelled. In the next workshop they wanted the group to account for their actions

as other opportunities had been missed, in order to support their efforts. These interactions revealed the growth in assertiveness of the women.

The research facilitators decided to investigate opportunities for skills development in the use of the media for the women.

#### **Action learning group 5: Media training**

The research facilitator from DPSA organized for some of the women to attend training on Gender and Communication at Media Works, a communication NGO in Cape Town. A few women were nominated to attend these workshops once a week over a period of four months. During the NAR workshops, the research facilitators were able to reflect with the women on how they could use these new skills:

*Facilitator: Is there no plan to get stories published that way and to know how to use media and get your stories out and how do we use Radio Zibonele or Radio Xhosa or newspapers or how are going to publish the stories?*

*CRW co-ordinator: We don't want Radio Zibonele because it's only in Khayelitsha. We want something that will be exposed to everyone.*

Another group was excited:

*We [will] go to the media because it is rare to find a disabled person on TV.*

The impact of the training was positive. The women reported back a few months later about a radio programme that they were involved in and how other women in Grabouw (a community approximately an hour's drive inland from Cape Town) had phoned to invite them to visit their group to assist with developing their skills.

In one incident, the training provided by Media Works brought out the tension and dynamics of inclusion and exclusion in development processes. The CRWs voiced to the co-facilitator that they felt that she decided who would go on the Media Works training. They felt that she should open the opportunity to them as well.

In closing this action story, it is evident that there was enormous potential to equalize opportunities, if the women are guided in the right direction and if they are linked up with similar provincial and national initiatives in public awareness and integration of disability into tourism and indigenous knowledge production.

## Appendix 12

### Messages for disability awareness

#### *June 16<sup>th</sup> – National Youth Day*

Community members don't look down upon our rights even if we are disabled we are like you, We want to fight for ourselves as well as the youth.

**Poem:** Up with the disabled person on this day of the 16<sup>th</sup>. You must remember disabled people. Us as disabled people are happy, we don't feel sorry for ourselves. We are like you people who are not disabled. Even you our youth expect great from us, trust us, respect us, support us and know that I'm your parent like any other days of your life. Respect me as well taxi driver. If I want to take a taxi give me a chance to get into the taxi. I am like other people; treat me as you. I have an input and contribution in your taxi even more than a person who is not disabled.

"Same way same spirit, it nice to be us because we are proud loud and passionate". Show who you are and don't lose hope, be sure of who you are and respect yourself.

**Disability can happen to everyone whether you are rich or poor.**

We want to educate our families about disability so that they don't look down upon us because of our disability because we are like them.

**The [disabled] youth must be powerful and take care of themselves and take care of their country, have a bright future and take care of their parents because the parents have created a brighter and beautiful future for us.**

#### *Aug 9<sup>th</sup> – National Women's Day*

*Disabled women pull up your socks and get up to fight for your rights. Nothing will come to your doorstep whilst you are sitting down.*

**The beliefs that we want to challenge are:**

- ♦ They do not expect you to be in love in an appropriate manner.
- ♦ They do not expect you to get married and have children.
- ♦ They don't see the need why you should look after yourself and be beautiful.
- ♦ They don't see you as a person who can work or have a small business.

**To us disability is like a photograph on the wall that does not have meaning. It doesn't mean anything to us. Talk about disability. Don't feel sorry for yourself, love yourself, be in peace with yourself and cleanliness will begin.**

- ♦ **Disabled people need love.**
- ♦ The family must accept a disabled person because s/he has rights like everybody else.
- ♦ They mustn't feel sorry for them and saying the handicapped,
- ♦ They must not be abusive.

*I want to change being called by names, being called handicapped and even if I'm walking people saying, "Shame that handicap". I want that to change as well whereby they say when I'm talking, "Don't listen to her, she is handicapped".*

Listen to us.



University of Cape Town

## Appendix 13

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MRC article

University of Cape Town

University of Cape Town

## Setting them free

*In a heart-warming collaborative research project, MRC-funded researchers help a group of disabled women come to terms with their impairment.*

Facing life with a physical disability is daunting - add to it the pressures of everyday life and it can become overwhelming. But for a group of disabled women living in wooden shacks in the Khayelitsha and Brown's Farm areas of Cape Town, life has taken on new meaning. In the words of one of the women: "I'm usually shy, but since I've been here I'm free."

Seeing me in a wheelchair also gave them confidence," says Ms Marjorie January

The women took part in a collaborative participatory action research project, which means that instead of just being research subjects, they were active participants in the process. The project started in 1998, when MRC-funded researchers from the University of Cape Town, the SACLA Health Project (a non-governmental primary health care organisation) and the Western Cape Provincial Disabled Women's Development Programme of Disabled People South Africa (DPSA) organised a series of workshops.



"I go where I want to go, because I'm not embarrassed anymore," says Ms Lindiwe Nyumbeka

In these workshops, the women related their experiences of being disabled. Ms Marjorie January from DPSA says: "They told us their problems, why they weren't doing what the other women were doing, what problems they were encountering in their families and the community at large and who they wanted to be in the future."

According to Ms January, most of them identified low self-esteem as a primary problem. "They felt the people at home were looking down on them - they weren't sure that they were good enough to do anything," she says.

According to UCT-based Ms Theresa Lorenzo, the disabled women identified the unavailability of transport as a big problem, since that prevented them from participating in community activities.

## DISABLED WOMEN ARE PROUD AND PASSIONATE

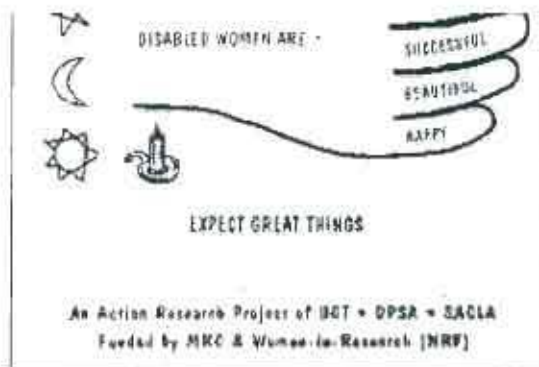


### Increased confidence

But the story doesn't end here. "The minute the women joined the group, they gained support. They were now among other people living with disabilities. Many of them said they never realised that there were so many disabled people," says Ms January.

This armed the women with a new sense of confidence and self-value. "In the beginning, they were asking us to help them with their problems such as transport and disability grants. Now they are looking for solutions





among themselves. Their increased self-esteem and assertiveness has given them the confidence to challenge the taxi drivers and they are now able to use public transport independently. It has been an empowering experience for the women," comments Ms Lorenzo.

After the initial story-telling workshops, the women are continuing to meet on a monthly basis. They now look at social issues of health, education, transport, work, employment and their families. The workshops have been

characterised by singing, dancing and using creative symbols and stories as a means of reflection by the disabled women.

Ms Peliwe Mdlokolo, a research assistant, says: "As the women were becoming more confident, they expressed an interest in developing their skills to empower themselves economically." The women have thus been linked with the Economic Empowerment Programme of DPSA, who help them with skills development, accessing loans and other support. "The women have now gained confidence that they can access resources - they're not so afraid now and they know where to find resources," says Ms Lorenzo.

The value of peer counselling has been evident throughout the workshops as Ms January is disabled herself. "They were able to see me as a positive role model. Being in a wheelchair, it was very encouraging to them. They could see me talking to them and that also gave them confidence," says Ms January.

#### T-shirts and CRWs

On the day of the MRC News' visit, the women were sporting very interesting T-shirts. "The shirts came out of a workshop focusing on the family. They tell a specific story - giving a message to their families. The symbols on the right-hand-side refers to providing for the family, while the moon and stars on the left symbolise the light that the research process has brought to them. That's the light that they now want to take into their communities," explains Ms Lorenzo.

And how have the shirts been received in the community? Eveline Japhta, one of the disabled women says: "They were fascinated. They are acknowledging disability now. They also see that we are doing something now - not just sitting at our houses. They acknowledge that we are 'able' as well."

The workshops have also changed the way the disabled women and community rehabilitation workers (CRW) feel about one another. "The disabled women have moved from a sense of powerlessness to confidence in taking responsibility to change their situations. They shared appreciatively that the CRWs are an important bridge in the rehabilitation process between them and the other service providers," says Ms Lorenzo.

"Our wish as rehabilitation workers is that the women will go forward - not backwards, so that we can see the fruit of the work that we are doing with them," says Ms Nomillion Fanteni, one of the CRWs.

Smiling towards a better future. Seated (fltr) are Phindiswe Mfakadolo, Peliwe Mdlokolo, Marjorie January, Nontibindim Nyithana. Standing (fltr) are Lindiwe Nyumbeka, Nozukile Mguda, Theresa Lorenzo and Eveline Japhta



#### Spirit of Ubuntu

"The women's stories reflect the many faces of Ubuntu - the age-old African philosophy of 'Umuntu ngumuntu ngabantu' meaning 'a person depends on persons to be a person'. The women have shown their ability to respond to their struggle against poverty and deprivation by

building trusting, co-operative networks among each other, their families and the wider community. The change that has occurred within the women reflects the values of Ubuntu, namely regaining dignity, developing respect, building solidarity, sharing compassion and moving beyond survival," says Ms Lorenzo.

Ms Lindiwe Nyumbeka, one of the disabled women, has the last word: "Before I came here, I never accepted my disability. I always wanted to cry when talking about it, because then I would think about the bad side of it. Now I'm becoming well. I accept my disability and realise it's not something to be embarrassed about. I'm like everybody else. I'm not shy anymore to walk outside. I go where I want to go, because I'm not embarrassed anymore."

**For more information about this project, please contact  
Ms Theresa Lorenzo**

at Tel: (021) 404-6043; or E-mail: [tlorenzo@uctgsh1.uct.ac.za](mailto:tlorenzo@uctgsh1.uct.ac.za)

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© Medical Research Council of South Africa, 2001 -  
PO Box 19070, 7505 Tygerberg, South Africa  
HO Tel +27 (0)21 9380911 / Fax +27 (0)21 9380200  
Enquiries: [webmaster@mrc.ac.za](mailto:webmaster@mrc.ac.za)

University of Cape Town





## Appendix 14

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### Stories of change

#### **Siphokazi: *We never believed in ourselves***

My first impression of Siphokazi was one of a feisty woman who had struggled in life and was able to stand up for herself. I met her long before the study started when I was doing home visits with the CRW. She was not afraid of telling a white person the hard life she had had. Her major concern was the difficulty of managing her disabled son and how she could generate an income to sustain her family. Her home circumstances were described in Chapter 5, cycle 3. Her story continues here:

*My father had a reason to call me Siphokazi meaning 'I will have great gifts'. But he died in 1977. I was too young. My mother was not there as she was training to be a traditional healer. After my father's death, I came to Cape Town to my brother.*

*I was excited to tell my story in the workshop, as I wanted help from the facilitators. I was brave enough to ask them if I could talk with them after the meeting. I did not know how to cope. It was difficult for me to get to the monthly workshops because the taxis did not stop for me. I usually arrived late. But I had a lot to share and I listened to the other women. I did not know what to expect from the workshops, but I wanted to learn how to make money and start a small business.*

*So I was determined to go to the training workshops on catering organized by SACLA. ... I felt very proud when I received a certificate at the end of the course. I went around showing my neighbours what I had made and let them taste it. They were very surprised. I felt GREAT! I am singing and dancing now. Especially now that I'm cooking, I even bring for the neighbour so that she can see Dyasi can cook.*

*I now offered that the women could work from my house to run a catering business until we found a space from the local council. I changed the front room of my house into an entertainment area where young people can come and play snooker and listen to music from the duke box. This helps keep the young ones off the streets. I also have a vending machine for chocolates and chips. In the afternoon and evening the room becomes a shebeen and I sell beer and cooked meals. Sometimes other women join me, which helps to break the loneliness by working towards the same goals. I invited another woman to join the group. Suddenly she realized that she was not the only one who is disabled. She also went for catering training. We want SACLA to carry on with us so that even at home they can stop feeling sorry for us. They like saying, "Don't do much, you are sick". Other women need to know that there are opportunities for learning skills to run our own businesses.*

*I know that some of the women in the workshops have not been happy with the progress. They say that we are waiting for the goal of these workshops that we have been doing to see if what they will make a difference. Some women feel that they have been coming, but there is nothing that they could say "here is something that we are coming with or that they helped us with". They feel that we need a way forward regarding our needs so that there can be more progress because there are still many women who are not working.*

*But things really started to change for us. One young woman in the group was excited since she was now able to perm her hair using her grant. So she felt more beautiful as she could be like her friends. Before I never talked about my disability, but now that I'm talking, I'm even respected by the taxi drivers. The taxi will stop and wait until I am settled in because they know I'm their best customer.*

*I was excited about the changes that occurred for me from going to the workshops. When I'm in workshops I see myself as a woman with dignity. I never believed in myself.*

Siphokazi was never afraid to tell things exactly as she experienced them. It was therefore very gratifying to be able to witness her change in mood that occurred during the study. She developed such a strong sense of her new identity as she participated enthusiastically in different training opportunities, which she was proudly of as her productivity increased. She was a witness to the power of healing from telling her stories.

### **Bongiwe: Beyond folded arms**

Bongiwe was an older woman who had a congenital deformity of the spine that caused a 'hunchback' and short stature. She was very active in the workshops. Her stories often had the group in laughter as she described how things had changed for her. She was employed temporarily at SACLA as a relief cleaner while the cleaner was on annual leave.

*I was not in the workshops from the beginning, but I heard about them from the other women. I decided to join. In some instances, the possibilities of learning different skills to make money have been more because of our link to SACLA and DPSA. Such opportunities helped us to provide for family needs. We feel we are much better than our neighbours. Some of our neighbour's are not working, but they don't do anything. Even though we are disabled, we don't like being dependent. We like doing our things so that we can feed our children. When I wake up I take a bucket and get sheep's heads and clean them so my children will have something to eat. We felt proud that we were the providers in our families. We are the breadwinners even though we are disabled. We buy clothes, chips, and sell, buy beef stock and eat nicely.*

*As a disabled person, I see myself just like other people because there's nothing that they can do that I can't do. If there is something bothering me, I like talking about it. Otherwise I get sick. So that makes me feel like everybody else who's not disabled. Even now I'm working with able-bodied people, I grow cabbage and I grow potatoes. So I see myself like everybody else.*

*I found out another woman who gardened. She told us how she had changed after going to training: "So I'm grateful to SACLA, they must carry on with me so that even at home they can stop feeling sorry for me because they like saying, "Don't do much, you are sick, you are a doctor's person". I plant in my garden, here in Cape Town. I got my first harvest in November and now I'm going to get my second harvest. I do that with my one leg and I just give myself breaks. It was great to hear her story.*

*In the workshops we also learnt that it was important to identify the changes that happened. Otherwise we become frustrated, as we don't see any difference or change. Although things with my family were not very bad before, my family has also changed in small ways. I told them that in these workshops we are discussing them so they better try and look into their behaviour. Since then sometimes I will just find someone from my family bringing me half a chicken and sometimes a child will just come and say, "My mother says I must bring this food for you".*

*Listening to the stories of other women helped us grow. Gubela had made clay women with different bodies. She explained what it meant to her: "I wish there was support to overcome the difficulties that we experience as women in development. My wish is that groups could be independent and stand for themselves. The folded arms here show me that in the groups, people have different problems. I wish that we would listen and respect each other and not go around making fun of other's problems". I was very happy sharing with others our joys and sorrow. Sometimes I used to worry because the CRW co-ordinator would always look as if she was unhappy. So I was happy that she looked happy today.*

*I've learnt a lot in these workshops. I couldn't talk before so I think that this group has helped me a lot. Another problem we recognised in our area is that disabled people are taken for granted. I wish we could have a place for disabled people to work in our area. When we are supposed to do something they won't come. I began to see how things had changed, as women found courage to speak out about their needs. We talked with the leaders there but no one seemed to care. They only care about us when it's time for voting. So the women are not listened to. That is why the women give up. I wish I could do something like toyi-toyi. I wish there could be development in our area because people go on and on and give up. Next year I'm hoping we can develop more.*

Bongiwe was an inspiration to the women and facilitators alike. She was not involved in the initial storytelling groups, but this did not hamper her development. She gained confidence from participating on the NAR workshops and integrated into local development projects where she lived. Her story reflects the diversity and difference amongst the women themselves. Her understanding of power dynamics helped her know how to address development needs in her community. She was no longer afraid to talk to local councilors about the needs and aspirations of the women.

## Nontsidiso: Becoming 'Intsika' - Pillars of strength

Nontsidiso's story captures the changes she experienced as a member of the women's group. It exemplifies how the multiple and complex sources of oppression and discrimination experienced by disabled people may be objectified and therefore rendered less potent through a process of enlightenment precipitated by dialogue, reflection and purposeful action. Knowledge and consciousness-raising became, for the women, a significant instrument of power and liberation.

Nontsidiso had a TB spinal deformity as a child, leaving her with a hunchback. It was however not her impairment that made her feel different from other children, but rather the poverty and the loneliness she experienced after the death of her parents as a young child. Nontsidiso was unable to complete her schooling due to poverty. As an adult and single parent, the absence of spousal support added to her load. Her abbreviated story follows. The underlined phrases allude to the interface between relexivity, action and change.

*I am Nontsidiso. I am 'intsika', a pillar of strength, because now there is nothing that I cannot do. I cried a lot when I told my story in the beginning, as I had never shared my story with other women before. I didn't feel I was different from other children when I grew up with a hunchback. We lived in the Transkei<sup>31</sup>. I came to Cape Town with my mother because she was sick. My mother died leaving me alone with her youngest child. Now I felt lonely and powerless because I had no mother, no father, not even an older brother who could help me. I don't have a sister. I had no money and used to ask for food from the neighbours. Now I saw that I was not like other children. Other children were not hungry; I was hungry. I dropped out of school because of money problems. Then I had two children of my own, but their father didn't help me. He is a drunkard and drug addict and he beats me. I called the police one day and they beat him. I have also reported my problem of being beaten in the community, but no one does anything. I was suffering and my children were suffering. Sometimes, friends and neighbours help me with food. I couldn't get a disability grant. Then I heard from the social worker about the women's group. I came because I wanted advice to help my children.*

*I was also in the group that went to the catering workshops as part of skills development in business. I didn't know that so much would come up with so little popcorn. I got a certificate now so that I can get a job in catering and do something with my hands. I didn't know that I could be taught and become educated. I see how I was able to change inside from believing that I could not manage to work. Now I am able to make mats that I learnt about at Philani Nutrition Centre<sup>32</sup>. I work on my own. Another man has promised to take me to a place to get material. Even with the beads, I don't ask anyone. I make them on my own.*

*My confidence increased, so did my hope and belief that the feelings and beliefs of my family and neighbours towards me would change. I wanted to change being called names. Even if I'm walking, people say, "Shame, that cripple". I wanted to change the way they say when I'm talking, "Don't listen to her, she's handicapped". I wanted to be seen on TV or to take a flight and then my family would say, "Oh her, we were looking down on her". The opportunity came for me to go with MJ to the national DPSA Women Achiever Award ceremony. The group was excited with me, clapping and rejoicing. Now it was my first time to go to Johannesburg. I was really excited about taking a flight. I was very thankful to MJ as she picked me up. Now I'm not scared of disability. I'll be someone one day. My family began to see me participating in national DPSA conferences. Before I could not go to occasions in the community because I was shy. Now I'm used to sharing with people from different areas.*

*I am happy since I met the CRW in my area who would give me her last R20 and MJ made me happy. I forgot totally that I don't have parents. I really appreciate what I get from other people. So if people are laughing at me now, I don't cry, so up with MJ.*

*We didn't know what to do after being disabled. The job of women in the community is to make the traditional African beer that is drunk by the men at special ceremonies. We were very excited when one of the women made a clay sculpture of the pot from which the men drink different African brews. The pot reminded other women of what they could do. When we sat down and thought about our future, we realised*

<sup>31</sup> a rural area in the Eastern Cape

<sup>32</sup> An NGO in Khayelitsha that provide nutrition programmes for children and skills development in income-generation for mothers and women

*we could make 'mqombothi' [African beer] and sell it. We realized that in this group we would succeed. We could make 'marewu' [sour milk] in this calabash whilst we're still alive so that we can succeed. So this pot (group) gave us life and a name in our community.*

Nontsidiso's story was heart-breaking, as it reflected so starkly the vicious cycle of poverty, which she recognized as more burdensome than her impairment. But the way she blossomed from interactions between the women during the workshops, and her enthusiasm in participating in catering was heart-warming for everyone. Her hard work was rewarded with an invitation to participate in national conferences, which was a further boost to her confidence. Her story also shows how women learnt to reflect on actions so that they were able to recognize changes in themselves.

### **Peliwe: *It's a long journey***

Peliwe's involvement as a research assistant and co-facilitator of the workshops in the study has been described in Chapter Four. Here, she shares her experience of the research process.

*For me this has been a challenge and a long journey. I came straight from university. When I met with the women, I was thinking, "Oh my God, how am I going to cope?" I didn't know where to start. I thought I had to go in and do things for them. Often as a professional I can get stuck on seeing the problems and the struggles. At that time [initial storytelling] the women were complaining about what they could not do, what they did not have.*

*But that has changed. After reading their stories I realised that there is so much to learn from each other. The journey was already taking place and the women were already doing something to influence their lives. So that was really a motivation for me. It is something that always gives me strength. I learnt through seeing how much the women were doing. It is a myth that the women are lazy and that they're not doing anything. These women aren't lazy. They are really doing a lot. The storytelling and action reflection process helped reflect back to us just how much everyone is doing and to build on these skills.*

*But it takes time; it's a long-term commitment to build our own capacity as well as the capacity of each other. Hopefully we won't allow others to just come into the community and do their own thing. We'll see that the community will gain from it. There has really been richness, a lot of fun, laughter and energy. I would like to encourage other professionals and students to take the same process of participatory action research for everyone to benefit. Being with the women and seeing us be ourselves has helped me to maintain my integrity. Seeing the women's hope when they have had nothing that has really been a powerful inspiration for me. So I want us to take the way forward, to go on and not stop.*

## Appendix 15

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Sample of poster

University of Cape Town







# "DRAWING WATER FROM THE WELL": the wishes of disabled women for social and economic transformation in the Western Cape, South Africa

## BACKGROUND AND CONTEXT

The experiences of disabled women living in shacks in the informal settlements of Khayelitsha in Cape Metropole, South Africa, are reflected here. The South African Christian Leadership Association (SACLA) Health Project is a non-governmental primary health care organisation working in these disadvantaged communities. The project has trained parents of disabled children as community rehabilitation workers (CRWs) to promote the rehabilitation, equal opportunities and integration of disabled children and adults. A collaborative venture was initiated in 1998 between:

Disabled Women's Development Project of Disabled People South Africa (Western Cape)  
SACLA Health Project and  
Department of Occupational Therapy, Faculty of Health Sciences, University of Cape Town

The purpose of the action research is to uncover the personal and collective barriers and strategies to equal opportunities for social development and economic empowerment as experienced by disabled women. Storytelling workshops for disabled women were facilitated in the areas where the CRWs work. The stories of the disabled women were reviewed using the Human Scale Development process as a framework for analysis.

## HUMAN SCALE DEVELOPMENT

HUMAN SCALE DEVELOPMENT is a process to encourage self reliance. The strategy considers the fact that "we live in a period of transition which means that paradigm shifts are not only necessary but indispensable" otherwise society will stagnate (Max Neef, 1991). Nine fundamental human needs are identified as the same in all cultures and historical periods (Neef).

SUBSISTENCE, PROTECTION, AFFECTION, UNDERSTANDING, PARTICIPATION, IDLENESS/REST, CREATION, IDENTITY, FREEDOM

Each need has a two-fold character which is held in constant tension, enabling the elimination of the vicious cycle of poverty:

- **WANTS** (desires) are psychological and a sensation that is felt in response to something that is missing;
- **NEEDS** (requirements) are the degree to which needs engage, motivate and mobilise people, and eventually become a resource (Max Neef, p24, 1991).

Basic needs are culturally determined, and vary according to time, place and circumstances. Measurement of Human Scale Development looks for qualitative growth of people and improved quality of life.

## BARRIERS/DEPRIVATION

BEING	HAVING	DOING	INTERACTING
<b>UNABLE</b> "When I lost anything I start having fits. I can't do anything with the problems I have in my legs and arms." <b>UNEMPLOYED</b> "I am not working."	<b>CULTURAL NORMS</b> "My mother had problems with her legs... waiting to sell a sheep [to help me], all she had."	<b>PROSTATE</b> "Unfortunately I fell pregnant / <b>EXPLOITED</b> "My family got the meat I am supposed to be selling. I worked for people who were not paying me for months."	<b>LOSS OF WORKPLACE</b> "After some time the [Khemtsha] workshop for disabled people was closed and I lost my job."
<b>POWERLESS</b> "I have not got a disability grant [DG] and I don't know why." <b>POOR</b> "My children were not at school because I could not afford it."	<b>LACK OF KNOWLEDGE</b> "I haven't received anything [about the DG] and nobody knows why." "The letter for the DG is still with me at home." <b>LACK OF SCHOOLING</b> "I left school at Std 4." "I have never been to school."	<b>LACK OF EDUCATING</b> "I don't have enough money to send the children to school." <b>LACK OF SUPPORT</b> "I don't know what to do with my [disabled son]."	<b>SCHOOL</b> "I have taken my [disabled son] out of school because he beats other children."
<b>HELPLESS</b> "I can't see a future and success with the present I am staying with."	<b>LACK OF SKILLS</b> "I don't know where to start / I don't know what to do now."	<b>UNABLE</b> "Recently I can't manage [work] anymore because of the attacks." "I stopped working because of the blindness."	<b>ISOLATION</b> "I am now at home not working."
<b>DEPENDENT</b> "The impact [of] my legs makes me dependent on other people like children and neighbours." "I am dependent on the DG." <b>HELPLESS</b> "Nothing seems to help." "Discharge I couldn't handle things very well with my hands."	<b>DISCRIMINATION</b> "The doctor was very angry with me... I went home and I was in very bad pain." "The doctor diagnosed and said that I had a leg off. I would be getting a DG." "I did not get a DG as the social workers say, 'what is it for?' as I am young." <b>INADEQUATE HEALTH AND SOCIAL CARE</b> "The hospital could not help me... they did not know what I had." "The day I received the DG for my child they scooped mine."	<b>CONFINED</b> "For a DG they said I had to go to the doctor who used to see me as a child." <b>INACCESSIBLE SERVICES</b> "I didn't go [to the welfare office] because I didn't have money." "It was difficult for me to attend treatment because there was no money." <b>MISTRUST</b> "My sister does not tell me why they are not responding to my DG application." "Initially I did not trust [the nurse]... I did not tell them my name."	<b>DOMESTIC VIOLENCE</b> "He beats me now... and everything." "I cry on a daily basis... he beats me day and night." "Two months ago I was beaten and injured by my husband in the same way... now it is worse." <b>SOCIAL ISOLATION</b> "I cannot talk to my neighbours as my husband will find me and beat me in front of them." "The street committee refused me back to my family but my family didn't come because I was far away."
<b>GRIEF/LOSS</b> "My parents died in 1981 and 1984." "Everybody at home loved me at that time." <b>LONELY</b> "I would be saying that I do not have any problems if it was not for my husband." "I don't have a husband." <b>SURVIVED</b> "Everybody in my family depended on me."	<b>FAMILY BREAKDOWN</b> "My children were not working or supporting me." "My eldest daughter was accepted for theft." "The father of my child is a drunkard and drug addict." <b>HELPLESSNESS WITH CHILDREN</b> "I have four children and I don't know what to do and where to get help."	<b>EXPLOITED</b> "Most of my family are drunkards so I look after them [children]." "My relatives are the ones who are abusing me financially." <b>UNHEALTHY</b> "I have tried to talk to [my family] but to no avail."	<b>ABANDONED</b> "My father died in 1977... and my mother was with traditional healers. I am staying alone."
<b>STEREOTYPES OF 'NORMAL'</b> "I wanted to be [a star]... and then I became disabled." "I have drawn myself as a fat person... because that is what my parents wanted for me." <b>HELPLESSNESS</b> "I am now feeling helpless." "So I gave up."	<b>ROLE LOSS</b> "Being the eldest I was supposed to help my mother because my father was dead." "My sister is responsible for everything."	<b>UNABLE - STEREOTYPES OF 'NORMAL'</b> "This disability has made me unable to do the things I would do as a normal person." "It's hard for me to live a normal life. I am unable to do anything."	<b>TIME OF IMPAIRMENT</b> "When I was 14 years old I was beaten by another child and I became paraplegic." "The eye problem became worse [when I grew older]." <b>PLACE OF IMPAIRMENT</b> "I fell in the garden in Transkei." "I was burnt in my shack five years ago." "I was hit by a bus and both my legs were broken."

## SUBSISTENCE

## UNDERSTANDING

## CREATION

## PROTECTION

## AFFECTION

## IDENTITY

## STRATEGIES/POTENTIALITIES

BEING	HAVING	DOING	INTERACTING
<b>INDEPENDENT</b> "I want to be fully independent like other people are having." "I want to be able to get a job. I want to be able to help people who are not helping them."	<b>SUPPORT</b> "My wish is to have things that other people are having." <b>SKILLS</b> "The doctor referred me to Khemtsha workshop for disabled people [where I was trained in sewing]."	<b>DISPELLING MYTHS</b> "I started sewing here to increase my profits... this was also successful." "The only thing that is in my way and not sewing." "I am trying to sell shoes & heads to help my problems." "I started selling food because I could get people to take me to the station."	<b>DISPELLING MYTHS</b> "I have been working in a nearby estate." "My mother and I still were working on farms."
<b>LEARNED</b> "I am going to ask the CRW to take a lesson that I can go to." "I would like to go back to school... I need a DG."	<b>SCHOOLING</b> "One of the CRWs told me they will try something so that my older child could go to school and that happened."	<b>PROACTIVE</b> "I want to know if there is anything I can do to relieve myself in this situation." "I would like someone to investigate why I didn't get a disability grant."	<b>COMMUNITY STRUCTURES</b> "I would like to know where to report my husband."
<b>HELPFUL</b> "I would like to be able to help other disabled people... to make a difference."	<b>SKILLS DEVELOPMENT</b> "I would like to do something better than [drawing lines] like sewing." <b>CURIOSITY</b> "I would like more advice on sewing because I am very interested."		<b>WORKPLACE</b> "My wish is to get another place where I can start sewing again." "If I had a sewing machine I would sew at home."
	<b>SOCIAL SECURITY</b> "On discharge I was given a letter to apply for a DG that was successful." "I received money for the bus accident." <b>HEALTH CARE</b> "They sent me to [the day] Hospital [then] they sent me to [a tertiary] Hospital."	<b>COMPLIANCE</b> "I have been attending [the day] hospital." "I take my treatment." <b>PROACTIVE</b> "I decided to go and see a doctor... he referred me to a [tertiary] hospital." "When that DG I am now buying and selling to increase my profits."	<b>COMMUNITY STRUCTURES</b> "Everyone [the boss me] I report him to the post in the street committee." "It is possible that they will build houses for disabled people only." <b>UPROOTING</b> "I was born in Transkei and came to Cape Town with my mother." <b>NEIGHBOURS</b> "I like by getting food from neighbours and friends."
	<b>FAMILY SUPPORT</b> "I have four children." "I am staying with my children." <b>ADVICE</b> "My mother said before she died I must take [money for bus accident] even if it was little."	<b>SHARING</b> "I would like to speak to you after this meeting... to relieve this situation." "I am looking after two children of my daughter." <b>PROCREATING</b> "Unfortunately I fell pregnant."	<b>FAMILY ACCEPTANCE</b> "Fortunately one of my brothers was in Cape Town so I came to him." "I am staying with my mother." "I left my child [in the Transkei] with my aunt."
<b>SELF-AWARENESS</b> "I don't want to feel helpless." <b>ASSERTIVE</b> "I am going to request my doctor to transfer me to some specialist." "I asked the doctor what was my problem... I didn't allow them to cut my leg since I was asking them to tell me what was wrong."		<b>RECOGNISE ABILITY</b> "I only do what I am able to do." <b>MEDITATE</b> "I used to light the candle when I pray to God for strength."	

## Acknowledgements

Siphokazi Gcaca, Colleen Saunders, Lana van Niekerk and Madie Duncan.

## Reference:

Max Neef, M.A. (1991) Human Scale Development: Conceptions, Applications and Further Reflections The Apex Press, New York and London.

THERESA LORENZO,

Department of Occupational Therapy, University of Cape Town, D.W.D.P. D.P.S.A, Western Cape.

MARJORIE JANUARY,

